

# AN INVESTIGATION INTO THE LIVED EXPERIENCES OF HIV- POSITIVE AFRICAN WOMEN LIVING IN THE UK

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A thesis submitted in partial fulfilment of the  
requirements of the University of East London for the  
degree of Professional Doctorate in Counselling  
Psychology

September 2013

# DEDICATION

I would like to dedicate this thesis to my grandmother, Ruby Hoslin. Thank you for your strength, your kindness and your love. Your belief in education was an inspiration to me and your tenacity taught me to never give up.

# ACKNOWLEDGEMENTS

My research would not have been possible without the participation of the five women who so generously agreed to be interviewed, and I would like to express sincere gratitude for their contribution. I would also like to thank Judith Kulaba at the Africare Trust for her support and help with the recruitment process.

Thank you to my research supervisor, Dr Kendra Gilbert, for her guidance and expertise offered on this subject and to Tara Kidd for her valuable input during the write up process. Many thanks also to my fellow trainees who have provided support, encouragement, advice and guidance throughout this process.

I am also exceptionally grateful to all my friends and family for their words of encouragement when I needed it the most and to my friends in Australia who were a source of inspiration in the last phase. Most importantly, I would like to thank my parents, Donovan and Andrea and my brother, Robert. Words cannot express fully how grateful I am to you for your constant love, patience, reassurance and belief in me. Your support throughout this incredibly long journey has been invaluable. Thank you. I love you all very much and I could not have done this without you.

## **ABSTRACT**

The number of African women living with HIV/AIDS in the UK is increasing. Until recently, research on living with HIV/AIDS has focused on quality of life issues; however, little is known about the experience of African women living as migrants in the UK with this condition. This study aims to contribute to the research literature by gaining an in-depth understanding of the lived experiences of black African HIV-positive women living in the UK and how they make sense of their experiences in relation to their individual sense of identity. Identity is defined by an interaction between the self concept and cognitive, social and biological experience and is re-evaluated and negotiated when faced with an HIV-positive diagnosis. Semi-structured interviews were carried out with five African women and their accounts were transcribed verbatim and analysed using interpretative phenomenological analysis (IPA). All participants had been diagnosed with HIV and had lived in the UK for a minimum of 5 years, spoke fluent English, and were over 18.

Five super-ordinate themes were identified: 1) Given life but it's a struggle, 2) A will to survive, 3) Positive coping, 4) Negotiating a stigmatised identity and 5) Recognising a new me. The results capture the participants' first hand phenomenological experiences of living with HIV in the UK. Whilst these women acknowledged the negative impact of living with HIV, they also talked about positive experiences and changes in their perceptions of themselves and their situation. They adapted to a life with HIV by adopting effective ways of coping in a country which few regarded as 'home'. Stigma had a profound impact on the women's lives, both relating to their ethnic identity and their HIV status and this made issues of disclosure and how health services were accessed a matter of concern. The women however demonstrated positive adjustment by attempting to reconstruct or renegotiate a coherent and culturally situated identity. The resilience of these women in dealing with challenges in their lives was enhanced by their cultural identity and associated perception of strength. In light of the findings, the study proposes that it is crucial to promote positive interactions with support structures and particularly a sense of community and kinship to ensure that HIV-positive black African women view themselves in a positive way. The results of the analysis are considered in light of existing theory and their clinical implications.

# CONTENTS

|   |            |
|---|------------|
| <b>DEDICATION</b>                                       | <b>I</b>   |
| <b>ACKNOWLEDGEMENTS</b>                                 | <b>II</b>  |
| <b>ABSTRACT</b>   | <b>III</b> |
| <b>CONTENTS</b>   | <b>1</b>   |
| <b>GLOSSARY</b>   | <b>5</b>   |
| <b>INTRODUCTION</b>                                     | <b>6</b>   |
| <b>CHAPTER ONE: LITERATURE REVIEW</b>                   | <b>8</b>   |
| 1.1 Current Clinical Definitions of HIV/AIDS            | 8          |
| 1.2 Estimates of Incidence, Prevalence and Prognosis    | 8          |
| 1.3 Living with HIV as a chronic illness                | 9          |
| 1.4 Chronic illness and identity                        | 10         |
| 1.5 HIV and identity                                    | 15         |
| 1.6 HIV-positive black Africans and identity            | 18         |
| 1.6.1 HIV positive black African women living in the UK | 21         |
| 1.7 Rationale for the current study                     | 23         |
| 1.7.1 Relevance to Counselling Psychology               | 25         |
| 1.8 Aims and research question                          | 26         |
| <b>CHAPTER TWO: METHODOLOGY</b>                         | <b>27</b>  |
| 2.1 A qualitative approach                              | 27         |
| 2.1.1 Rationale for qualitative research                | 27         |
| 2.2 Epistemological considerations                      | 28         |
| 2.3 Interpretative phenomenological analysis (IPA)      | 28         |
| 2.3.1 Rationale for using IPA                           | 29         |

|            |  |           |
|------------|--|-----------|
| <b>2.4</b> | <b>Reflexivity</b>   | <b>31</b> |
| <b>2.5</b> | <b>The sample</b>  | <b>32</b> |
|            | 2.5.1 Recruitment  | 33        |
|            | 2.5.2 Inclusion criteria   | 34        |
| <b>2.6</b> | <b>Ethical considerations</b>  | <b>34</b> |
|            | 2.6.1 Informed consent   | 34        |
|            | 2.6.2 Confidentiality  | 35        |
|            | 2.6.3 Potential distress   | 36        |
| <b>2.7</b> | <b>Data collection</b>   | <b>36</b> |
|            | 2.7.1 Semi-structured interviews                                       | 36        |
| <b>2.8</b> | <b>Data analysis</b>   | <b>38</b> |
|            | 2.8.1 Analysis of individual transcripts                               | 38        |
|            | 2.8.2 Emergent themes  | 39        |
|            | 2.8.3 Cross case analysis  | 39        |
| <b>2.9</b> | <b>Validity and quality</b>  | <b>40</b> |
|            | 2.9.1 Sensitivity to context   | 40        |
|            | 2.9.2 Commitment and rigour  | 41        |
|            | 2.9.3 Transparency and coherence                                       | 41        |
|            | 2.9.4 Impact and importance  | 41        |
|            | <b>CHAPTER THREE: RESULTS</b>  | <b>42</b> |
| <b>3.1</b> | <b>Overview</b>  | <b>42</b> |
| <b>3.2</b> | <b>Super-ordinate themes and related sub-themes</b>                    | <b>43</b> |
| <b>3.3</b> | <b>Introduction to the themes</b>                                      | <b>44</b> |
| <b>3.4</b> | <b>Theme one: Given life but it's a struggle</b>                       | <b>45</b> |
|            | 3.4.1 "...there's a constant internal battle that goes on with myself" | 46        |
|            | 3.4.2 Medication: Friend or foe  | 47        |
|            | 3.4.3 "Life is like a prison"  | 49        |
|            | 3.4.4 Letting go of who I was  | 50        |
|            | 3.4.5 Summary  | 53        |
| <b>3.5</b> | <b>Theme two: A will to survive</b>                                    | <b>54</b> |
|            | 3.5.1 "That's strong minded is what it is, Africa is strong."          | 54        |
|            | 3.5.2 The value of support groups                                      | 57        |
|            | 3.5.3 Defending against social stigma                                  | 59        |
|            | 3.5.4 Summary  | 62        |
| <b>3.6</b> | <b>Theme three: Positive coping</b>                                    | <b>63</b> |
|            | 3.6.1 Doing vs being   | 63        |
|            | 3.6.2 "My body is shining; you can't even know I'm positive."          | 66        |

|   |  |            |
|---|--|------------|
| 3.6.3   | Summary  | 67         |
| <b>3.7</b>  | <b>Theme four: Negotiating a stigmatised identity</b>      | <b>67</b>  |
| 3.7.1   | Keeping the identity secret                                | 68         |
| 3.7.2   | “We are black and we have HIV so we have both hard things” | 70         |
| 3.7.3   | Summary  | 71         |
| <b>3.8</b>  | <b>Theme five: Recognising a new me</b>                    | <b>71</b>  |
| 3.8.1   | Summary  | 73         |
| <b>CHAPTER FOUR: DISCUSSION</b>   |  | <b>75</b>  |
| <b>4.1</b>  | <b>Overview</b>  | <b>75</b>  |
| <b>4.2</b>  | <b>Control</b>   | <b>76</b>  |
| 4.2.1   | Internal dilemmas  | 77         |
| 4.2.2   | Experiences of loss  | 78         |
| 4.2.3   | Summary  | 80         |
| <b>4.3</b>  | <b>Resilience</b>  | <b>81</b>  |
| 4.3.1   | Strength of an African culture                             | 81         |
| 4.3.2   | Defending the identity                                     | 84         |
| 4.3.3   | Summary  | 85         |
| <b>4.4</b>  | <b>Positive adaptation</b>                                 | <b>85</b>  |
| 4.4.1   | Keeping busy   | 86         |
| 4.4.2   | Externalising the impact of HIV                            | 87         |
| 4.4.3   | Living with stigma   | 88         |
| 4.4.4   | Summary  | 89         |
| <b>4.5</b>  | <b>Positive growth</b>                                     | <b>90</b>  |
| 4.5.1   | Summary  | 91         |
| <b>4.6</b>  | <b>Original Contributions</b>                              | <b>92</b>  |
| <b>4.7</b>  | <b>Clinical Implications</b>                               | <b>94</b>  |
| 4.7.1   | Recommendations for counselling psychologists’ practice    | 95         |
| <b>4.8</b>  | <b>Critique of the research</b>                            | <b>98</b>  |
| <b>CONCLUSIONS</b>  |  | <b>102</b> |
| <b>REFERENCES</b>   |  | <b>104</b> |
| <b>APPENDIX</b>   |  | <b>114</b> |
| <b>Appendix 1: Response from ‘Africare Trust’ for participant recruitment</b> |  | <b>114</b> |

|   |            |
|---|------------|
| <b>Appendix 2: Time slot for presentation at the ASHN Conference</b>                        | <b>115</b> |
| <b>Appendix 3: Ethical approval</b>   | <b>116</b> |
| <b>Appendix 4: Participant invitation letter</b>  | <b>119</b> |
| <b>Appendix 5: Participant information sheet</b>  | <b>122</b> |
| <b>Appendix 6: Participant Recruitment Poster</b>   | <b>124</b> |
| <b>Appendix 7: Informed consent form</b>  | <b>125</b> |
| <b>Appendix 8: The sample and participant demographics</b>                                  | <b>126</b> |
| <b>Appendix 9: Smith's (2001) guidelines for quality in IPA research</b>                    | <b>127</b> |
| <b>Appendix 10: Interview schedule</b>  | <b>128</b> |
| <b>Appendix 11: Key for the presented extracts in the results section</b>                   | <b>129</b> |
| <b>Appendix 12: Illustrative quotes for master themes and subthemes</b>                     | <b>130</b> |
| <b>Appendix 13: Annette's Interview Transcript</b>  | <b>140</b> |
| <b>Appendix 14: Reflections of Annette's interview from reflexive diary-example section</b> | <b>154</b> |
| <b>Appendix 15: Paper Trail</b>   | <b>155</b> |



## **GLOSSARY**

**AIDS** - Acquired Immune Deficiency Syndrome

**BME** - Black Minority Ethnic

**BPS** - British Psychology Society

**HAART** - Highly Active Anti-Retroviral Therapy

**HIV** - Human Immuno-deficiency Virus

**IPA** - Interpretative Phenomenological Analysis

**NHS** - National Health Service

**SOPHID** - Survey of Prevalent HIV Infections Diagnosed

**UNAIDS** - The Joint United Nations Programme on HIV/AIDS

# INTRODUCTION

Recent years have brought about dramatic changes to the HIV/AIDS epidemic that have enabled better stability in the health of a number of people living with HIV and in particular, reducing the number of AIDS related deaths (UNAIDS, 2008). This movement however; although positive, initiates new challenges such as understanding how people live with HIV. The ways in which HIV positive individuals perceive and interpret themselves within broader societal relationships is significant in altering their identity (Tsarenko & Polonsky, 2011). Therefore adopting a qualitative approach such as interpretative phenomenological analysis (IPA) which aims to “explore in detail how participants make sense of their personal and social world” (Smith & Osborn, 2003; p. 51) seems appropriate.

Counselling psychology has a responsibility to the wider society which encompasses research and applied work in several broad domains, including health (Gelso & Fretz, 2001). In order for the field to have an influential role in service delivery and policy formation that benefit individuals with chronic health conditions, there is a need to participate in, promote, and reward interdisciplinary research and application. Counselling psychologists strive for knowledge about diverse life experiences of their clients and challenge pathologising perceptions which are based on social discrimination. Werth (2008) and colleagues argue for an infusion of counselling psychology expertise at all levels of therapeutic activity to promote the health and well-being of individuals living with HIV.

The focus of contemporary health and psychology research predominantly addresses the concerns of the affluent western world. International health inequalities can make it difficult to ascertain meaningful cross-cultural insight that might extend beyond the divide between affluent and research-poor countries (Flowers et al., 2006). This is particularly true when considering HIV in the UK. Therefore the current study aims to explore the individual, subjective experiences of a group of HIV positive black African women living in the UK with the purpose of highlighting unique perceptions and ways of making sense of their lived experiences of HIV and sense of identity. Ultimately, the study aims to use the findings to contribute to an under-researched area and inform clinical practice involving this particular participant group. Despite its use, it is acknowledged that the term ‘African’ implies homogeneity within a heterogeneous

group of individuals comprising of various cultures, languages, tribes, religions, nationalities and ethnicities (Elam, Fenton & Johnson, 1999). Chapter one presents the relevant literature in the field however; it is not an exhaustive review; instead, contributions have been presented according to their relevance with the aim of informing the reader about the background and motivation behind the current study.

# **CHAPTER ONE: LITERATURE REVIEW**

In this chapter I will describe the existing literature by first looking at HIV and AIDS definitions and statistical data as well as the current consideration of HIV as a chronic illness. Then I will introduce literature on the specific participant group being investigated and provide a rationale for investigating identity in relation to the topic. I will then provide theoretical considerations of the psychological concept of identity in line with my epistemological position and a phenomenological approach and how it is situated in an African context. Research on identity and chronic illness in general will be presented. This will be followed by findings on identity and HIV, in particular, which will include a review of the two studies found specifically on HIV-positive black Africans, in the context of identity. I will conclude the chapter by discussing the work that has led to the current research issue and why this issue is important and relevant to counselling psychology.

## **1.1 Current clinical definitions of HIV/AIDS**

Acquired immune deficiency syndrome (AIDS) is an infectious disease caused by the human immunodeficiency virus (HIV). HIV is the cause of the spectrum of disease known as HIV/AIDS (WHO, 2007). AIDS destroys the body's ability to fight infections and other life-threatening illnesses. AIDS develops in a person with HIV after years of infection, as HIV progressively weakens the body's immune system and increases its susceptibility to tumours, tuberculosis, pneumonia, diarrhoea and other opportunistic illnesses (Dore & Cooper, 2006). HIV and AIDS medical treatment is focused on improving the quality and length of life for those infected, by slowing or halting the replication of the virus and treating or preventing infections and cancers that often develop in people with AIDS.

## **1.2 Estimates of incidence, prevalence and prognosis**

Information gathered from the UNAIDS (2012) report on the global HIV/AIDS epidemic shows that the number of people infected with HIV/AIDS has dropped to around 34 million at the end of 2011, compared with around 40 million in 2004. According to the UNAIDS HIV and AIDS estimates (2011) 94,000 people are living with HIV/AIDS in the UK. Sub-Saharan Africa remains most severely affected, with nearly 1 in every 20 adults (5%) living with HIV/AIDS and accounting for 69% of the people living with

HIV/AIDS worldwide. Information on prevalence of infection in the UK (SOPHID) shows that in 2011, over 34% of the 73,659 people seen for HIV care were of black African ethnicity with women making up 66% of this figure (Department of Health, 2005). There is no cure for HIV, however since protease inhibitors, also referred to as HAART (Highly Active Anti-Retroviral Therapy), were introduced in 1996, the biomedical effects of HIV have drastically improved (Rofes, 1998), enabling people with the virus to stay healthy and live longer (NHS Choices, 2012). HIV is now considered a manageable chronic illness in the US (e.g., Baumgartner & David, 2009) and the UK (e.g., Doyal & Andreson, 2005) due to access to life-extending medications.

### **1.3 Living with HIV as a chronic illness**

In addition to improved immune and physical functioning, people living with HIV who have access to HAART could experience a better quality of life than before the medical advancements (Marins et al., 2003) and this has become an important focus for researchers and health care providers (Clayson et al., 2006). Living with a chronic illness such as HIV however, means coping with a range of symptoms related to the infection, comorbid illnesses or side effects from medication (Halloran, 2006) for long periods. In addition to physical effects, many struggle with psychosocial problems such as poverty, stigma, depression and social isolation and these have been shown to be associated with stress and depression (e.g., Hays, Turner & Coates, 1992). Attending to daily tasks of living, physical activity or an active social life can be a challenge to many HIV-positive individuals. Low energy levels and fatigue are associated with negative psychological as well as physical effects (Breitbart et al., 1998).

Coping with HIV by avoidance was associated with increased levels of stress (Schmitz & Crystal, 2000) as well as poor social functioning due to social withdrawal (Fleishman et al., 2000). In addition, Crystal et al., (2000) suggested that coping by avoidance reduces productivity due to the limitation of complex role functioning, such as work or education, in HIV-positive individuals. Fleishman et al., (2000) also proposed that denial correlated with low self-esteem and depression in individuals with HIV. A review of research on HIV-positive sub-Saharan African migrants in the UK, by Prost, Elford,

Imrie, Petticrew and Hart (2008) showed that accessing healthcare and social services was hindered by awaiting immigration status, social isolation, discrimination, and HIV related stigma. High levels of unemployment and poverty were also reported. These findings on HIV as considered a chronic illness however; resulted from quantitative research methods and although much of this research has been useful in terms of establishing issues around quality of life, it has not considered how such issues are experienced and impact upon the way HIV-positive individuals perceive themselves.

#### **1.4 Chronic illness and identity**

It has been suggested that chronic illness undermines one's sense of self and therefore much qualitative research in this area is framed around issues of identity (Inder et al., 2011). Chronic illness is often accompanied by various personal and lifestyle changes such as loss of work, loss of social networks, abandonment of meaningful activities and functioning, intrusion of disempowering medical regimens into daily life, increased dependence on others, social stigma and uncomfortable emotions such as anxiety (Charmaz, 1993; Lundmark & Branholm, 1996). Together, such profound life changes may become a threat to an individual's familiar sense of self and identity (Bury, 1982). Therefore, many studies on chronic illness have framed illness as a 'biographical disruption' (e.g., Charmaz, 1995) or the altering of social interaction due to the added burdens of the illness (Tewksbury & McGaughey, 1998). The literature on identity and chronic illness includes themes about avoidance (denial), adaptation, loss, disclosure, transition and positive growth (positive adjustment).

Responses to biographical disruption and identity threat were identified by Charmaz (1995) as: ignoring and minimizing (whereby the significance of the disease is rejected and potential identity transformations may be averted) and adaptation (whereby the altered body and illness identity is integrated into the self and the individual surrenders to the illness experience and consequences). The role of 'acceptance' and 'denial' in coming to terms with a chronic illness seemed to feature extensively throughout the literature relating to identity however these terms appeared to be too simplistic. Telford et al. (2006) conducted a literature review on these concepts which have been explored using psychoanalytic theories on death and dying and they are often referred to in descriptions of individual responses to chronic illness. It could be argued

however, that reliance on an acceptance-denial framework when trying to understand the illness experience detracts from the voices of those experiencing it. According to the review of the relevant research on acceptance, denial and chronic illness, in some instances, denial is an adaptive response to illness, and acceptance was not always found to be the ideal outcome (Telford et al., 2006).

Biographical disruptions however often cause great distress for chronically ill people. In particular, Charmaz (1983) identified four social psychological conditions which may amplify a sense of loss of self for chronically ill individuals. These are: living a restricted life such as becoming physically impaired or homebound; living a socially isolated life such as withdrawal from social life due to stigma, rejection or discrimination; experiencing discredited definitions of self whereby strangers may perceive symptoms/behaviour as voluntary misconduct and lastly a fear of becoming a burden on others. Clair, Beatty and MacLean (2005) reviewed literature on managing invisible social identities, including chronic illnesses which are 'invisible', in the workplace. Their review raises issues about stigma and disclosure. They suggest that chronic illness may be out of sight but not necessarily out of mind. In particular, individuals with chronic illness are likely to strategically consider when and how to reveal their illness, given the costs associated with social stigma surrounding certain illness such as HIV. They maintain that revealing or hiding ('passing') information about the self is central to managing individual perception of themselves and how others perceive them. Therefore if an illness is invisible, it may permit a degree of control over biographical disruptions.

Transition towards a positive identity in the face of loss caused by disruptions from chronic illness is proposed to occur through two processes; reconnection with valued aspects of the pre-illness self and the development of new, meaningful social identities (Becker, 1997). This process in chronic illness was described by Corbin and Strauss (1988, p. 266) as "discovering what aspects of self remain and can be carried forward to provide biographical continuity, and...what new aspects can be added...to give new meaning to biography." For example, Charmaz (1994) used grounded theory to analyse spoken and written accounts of chronic illness in men as it is experienced as an identity. A dilemma was noted between identity standard and the illness identity. A male identity standard commonly has a strength component and if illness

compromises body strength, the identity standard will no longer fit. An identity transition needs to occur in order to reduce psychological distress and maintain a sense of coherence about his life (Charmaz, 1994).

Aspring (2001) described how women with chronic fatigue syndrome (CFS) and fibromyalgia create new concepts of identity after the onset of illness, and how they come to terms with their newly arisen identities. She found biographical disruptions which had consequences for identity, particularly in work and social life. The women tended to come to terms with their new identity by partly transforming their earlier identity in relation to their current situation. However, many of the women also experienced illness gains in relation to the new identity, such as new insights. Therefore biographical disruption and illness experience involved losses and gains that had consequences for identity (Aspring, 2001). This is in line with Charmaz's (1993) claim that identity renegotiation takes place when clients start to see themselves in new roles that have meaning and find new strength due to or in spite of an illness. Despite these relevant findings, Aspring (2001) was influenced by symbolic interactionism which focused on the illness experience reflected in social structures rather than the illness experience alone. She endeavoured to obtain a breadth of variation rather than individual experience by using a large sample size to reveal collective results.

According to Whittemore (2005), integration of an illness experience into individual identity results in improved psychological adjustment. From a phenomenological perspective, it is this internal psychological adjustment to subjective experience which leads to transitions in identity. However, phenomenological approaches do acknowledge a need to consider the social and linguistic make-up of identity and experience as well as a sense of the individual, coherent and subjectively 'true' nature of individual subjectivity (Crossley, 2000). Haslam, Jetten, Postmes & Haslam (2009) presented ideas within a social identity framework as a basis for understanding health issues and, in line with social identity theory, encouraged psychologists' engagement with the complexities and richness of the broader world.

Taylor's cognitive adaptation theory (1983) proposed that life-threatening events activate three themes: a search for meaning, mastery, and self-enhancement. She



maintained that individuals strive to create meaning of events to make sense and re-establish coherence to their lives, as such re-establishing biographical continuity which is lost following a life-threatening diagnosis. Identity is an ambiguous term and the literature reveals diverse assumptions about what Identity is. Identity was described by Erikson (1968) as subjective and involving a sense of self-sameness and stability over time. However he suggested that traumatic events can disrupt the continuity which is crucial to the maintenance of coherent identity.

Gergen and Gergen (1988) rejected the traditional positivist assumptions in empirical social psychology and described identity as a sensible result of an individual's life story which is re-narrated as a vehicle for identity construction. Engaging in meaning-making to achieve coherence and comprehensibility (schema change) means individuals not only discover new meaning but a new sense of themselves (Brennan, 2001). An individual is a product of his/her lived experiences which are experiential realities, real to the individual but uniquely interpreted; therefore both illness and identity reflect something of a realist ontology while also being shaped by cognitive, social and biological interpretations. Research suggests that part of successfully coming to terms with trauma is a new sense of identity (Neimeyer, 2006). Some researchers (e.g., Erikson, 1968) argue that identity is static but others (e.g., McAdams, 1993) argue that identity is not only dynamic, but influential in shaping our lives. However more recent qualitative studies have suggested that at the core of the survivor experience is an identity shift which is considered a coping strategy as well as an outcome and may influence the illness trajectory or adjustment process (e.g., Patterson, 2001; Inder et al., 2011).

A study by Vignoles et al. (2006) introduced the concept of 'identity motives' which they consider to be outside of conscious awareness but are inferred and reflected in desires and future identities. They maintain that individuals attempt to avoid negative emotion or social exclusion and achieve future selves which enhance self-approval and self-worth. This is in keeping with Taylor (1983) who maintained that positive adjustment can often be illusory but self-enhancing. This research highlights the need for acknowledgment of personal agency in identity re-construction towards a potentially more powerful sense of identity (Thoits, 1999). Identity also appears to shape appraisal, coping and adjustment. Therefore, gaining a better understanding of

the influence of identity on health behaviours and associated psychology is necessary. Models of identity and illness illustrate the impact of illness on identity and the impact of identity on the illness experience (Inder et al., 2011).

The initial challenge of using identity to explore the psychosocial issues of HIV is in the term itself. 'Identity' appears to reflect "diverse theoretical conceptualisations and is an essentially contested concept" (Mathieson & Stam, 1995, p. 287). In the current study, I have adopted the view that 'self', 'identity' and 'self-concept' all represent part of the process of developing a sense of who an individual is (Schwartz et al., 2010) so they will be used interchangeably throughout. The way in which we perceive ourselves, (e.g. self, self-concept, identity) has profound effects on the way we feel, think and behave (Van Knippenburg et al., 2004) and has thus been a widely investigated concept within psychology.

Identity has been conceptualised in a number of ways by researchers as shown in the presented literature, for example Erikson's (1968) view of identity as purely fixed and unchanging; however the position taken by Vangeli and West (2012) on the concept of identity is the position taken in the current study. They looked at identity transition from a phenomenological perspective and refer to identity as the "object of our perceptions when we contemplate ourselves" (p.172). It is a phenomenological result of an individual's construction of meaning and cognitive appraisal (Tafarodi, 2008). They view identity as a constellation of self-aspects which are socio-cognitive categories derived from interaction between identity and social experience (Linville, 1985). These are generally referred to as 'identities' in the literature. Identity is therefore constantly re-evaluated and negotiated in relation to the inner self and lived experience. This perspective defies reductive statistical analysis of quantitative research on which many traditional identity theories are based. As medical science has progressed so that HIV is considered manageable, the identities of people living with HIV have also changed (Green, 2009). There is a need to understand how HIV-positive individuals make meaning and potentially re-construct a positive sense of identity.

## **1.5 HIV and Identity**

Although there is literature exploring the impact of HIV in general (largely from a pre-HAART era), there is less research examining the contemporary impact of HIV; and even less qualitative research, particularly those studies examining HIV and identity. The literature on HIV and identity however; revealed themes about HIV identity salience, the impact of HIV on other identities, turning points, education, social stigma, social support and psychological ownership (acceptance).

An HIV or AIDS diagnosis means an individual needs to grapple with incorporating that identity into the self in some way (Baumgartner & Niemi, 2013). Studies concerned with HIV and identity before the development of HAART found that coming to terms with the progression of HIV often precipitates a re-definition of identity and that HIV tends to become an individual's most salient part of their identity (Sandstrom, 1990; Tewksbury & McGaughey, 1998). More recent research however; suggests that after the implementation of HAART, HIV has become more integrated with other identities and may not be the most salient identity (e.g., Baumgartner & David, 2009). This is significant because it was found that individuals who adopt a 'patient' identity allowing their illness experience to define them, are more likely to report psychological distress and disruption in their lives than those whose illness does not define them (Park, Zlateva & Blank, 2009).

A recent qualitative study by Baumgartner & Niemi (2013) critiqued the literature on the impact of HIV on various identities including spirituality, work and motherhood. According to their review, spirituality and work served as a "context for perspective shifts or new meaning making" (Baumgartner & Niemi, 2013, p. 3). They state that spirituality has been found to contribute positively to mood and better health. However these were positivist findings from quantitative research methods and did not result from subjective individual experience. A gap in the literature led them to investigate the effect of HIV on other less researched identities by interviewing 36 HIV-positive individuals in the US and they found changes in work, intimacy, spirituality, addiction and parent identities. Their sample however; was heterogeneous and the focus was on the inter-relation between identities in the face of an HIV diagnosis. Their study did

not provide insight into the impact of HIV on the individual's sense of identity itself (which would naturally uncover insight about other identities).

Baumgartner & David (2009), who investigated a heterogeneous group of 14 HIV-positive individuals in the US, emphasised the value of turning points and HIV education in positively incorporating HIV into one's sense of identity, which they termed the 'integration' phase. The turning point was often related to health status and medical intervention. As a result, participants integrate their HIV status as a part of the self and the salencies of other identities adjust in order to reflect the addition of a new and individualistic integrated identity. Social stigma and an inability to find a suitable support group had a negative effect on the incorporation process. Very little literature however was found on investigating the experience of Baumgartner & David's (2009) integration stage which is involved in the phenomenon of identity transition.

Tewksbury and McGaughey (1998) however used a pendulum model which assumes a fluid movement between "sick" and "healthy" statuses and centralised the altered body to explore how 63 HIV-positive gay (mostly) men in the US develop and adopt HIV-related identities. They focused on experience of HIV in the body and how physical effects are perceived as biographical disruptions (Bury, 1982) which elicit physical and social responses and lead to identity constructs; the outcome of movement along the pendulum. Although the body cannot be ignored in the HIV experience, Tewksbury and McGaughey (1998) assumed it to be at the forefront. Their method was reliant on Charmaz's (1995) pre-determined theory about responses to biographical disruption, mentioned above (ignoring and minimising or adaptation) which reflected a deductive approach to analysis and had the potential to diminish the voices of the participants. Their results suggest that the impact of HIV on the self is dependent on experiences, both objective and subjective, of an altered body and social interaction. Their study however; said more about outcome than experience of the identity transition process. Charmaz (1995) considered adapting to be about struggling with instead of against the illness. Tewksbury & McGaughey (1998) however suggested "catastrophising" as an additional response whereby an individual expects the worst from the disease and feels powerless. They proposed that Charmaz's (1995) adaptation phase comprised of three phases namely, experience of an altered body, reformulation of philosophical frameworks and surrendering to the

illness experience. They maintained that total adaptation involves self-acknowledgement of the incorporation of an HIV identity and an accomplished sense of a valued self.

A more recent Australian study on identity transition was carried out by Tsarenko and Polonsky (2011, p.465) which introduced HIV is an “undesired possession that people accept to varying degrees” and they referred to this acceptance as “psychological ownership”. They looked at the interplay between “undesired possession” and its ownership to better understand identity transition among 15 people living with HIV. They proposed that the level of ownership (health or illness) shapes the individual’s identity and he/she evolves based on what has been acquired rather than lost. Their study contradicts that of Baumgartner & David (2009) firstly because they believe that the transition process is not linear and involves many variable and repetitive progressions and secondly because they maintain that some people negatively proceed towards their new identity often moving from a state of detachment to one of control over their new status. They are however in agreement that the underlying meaning of identity reconstruction, through an endless process of negotiation, is highly individualistic.

They showed that not only does being HIV positive impact on identity transition but goes a step further facilitating the acquisition of a new reconstructed identity through their active engagement with support structures (Tsarenko & Polonsky, 2011). “Active engagement (i.e. taking ownership) promotes the transition to a positive identity thereby improving one’s own welfare” (Tsarenko & Polonsky, 2011, p. 479). They adopted a hermeneutically grounded interpretative framework which allowed a rich subjective and reflective interpretation of personal narratives and experiences. Identity is defined by the inner self’s interaction with the social world, therefore participants’ life stories are the most effective medium for the researcher to understand self-constructed identity with particulars of events which are perceived as significant to the participants.

In sum, the literature presented on chronic illness, HIV and identity is based on varied theoretical standpoints. Holloway (2005) posits that positivism, employing quantitative enquiry, is unable to answer certain questions of meaning, subjective truth, and

biographical inconsistency. Social constructionists (e.g. Potter & Wetherell, 1987) view identity as entirely dependent on language and linguistic constructs which are adopted and used to conceptualise ourselves and others. Phenomenology however recognises inter-subjective meaning where knowledge is not 'found' but constructed by the participants. Traumatizing experiences such as chronic and life-threatening illness disrupt routine and 'taken for granted' expectations and the individual attempts to re-establish a sense of order and meaningfulness as well as their sense of identity (Crossley, 2000). This ultimately shapes how they manage the disease. Therefore, identity is best conceptualised by a theoretical approach which recognises linguistic and discursive structuring of identity and experience while also appreciating a sense of personal experience and reflexivity and the coherent and 'real' nature of individual subjectivity (Crossley, 2000). The impact of illness on identity is commonly viewed as negative, yet Dibb & Kamallesh (2012) and studies on cancer patients (e.g., Arpawong, 2013) have reported post-traumatic growth which is often characterised by a renewed appreciation for life and sense of identity. Therefore, an exploration of how HIV-positive black African women's identity is re-evaluated when faced with an HIV-positive diagnosis is key to understanding the phenomenological nature of their lived experience.

## **1.6 HIV-positive black Africans and identity**

Identity theories such as those mentioned above are based on western perceptions of identity which may be inadequate in terms of the social and cultural realities of an African context and in terms of the implications for HIV research (Tafarodi, 2008). Researchers have argued that it may not be helpful to separate the mechanisms of individual identity and social identity when dealing with African contexts (e.g., Boram-Hays, 2005). "The essentially humane and moralistic ideas, beliefs and customs among the Africans are the non-material aspects of their African culture which the individual African in his socialisation or upbringing has imbibed and internalised into his personality" (Quoted in Oyeshile, 2004, p.302). For example, the motherhood identity is considered central to African communities (Airhihenbuwa, 2007) because the strongest social connections are built on matriarchal lineage. The woman is defined in terms of her role as a key figure in the household and family. This identity is enacted in many common African concepts such as motherland, mother tongue,

motherhood, and mothering (Nnaemeka, 1997). On the other hand, an inflexible view of African identity would not be realistic in the face of modernity (Oyeshile, 2004). As individual identity is inherently positioned within social structure, people living with HIV will not only re-evaluate and negotiate their self-concepts but will potentially conceptualise HIV in relation to the social group, community or family.

An additional argument presented by Smith-Lovin (2003) refers to the ways in which social identities are linked and inseparable in their impact on an individual's life. This is reflected in Bowleg's (2008) critique of identity research which argues that most theory and research on identity assumes identities to be separate and therefore measurable as independent constructs (e.g., Burke, 2003; Stryker, 1980). Bowleg (2008) maintains that attaching identities of Black, Lesbian and Woman is not the same as studying the experience of Black, Lesbian, Women because the marginalised identities have strong ties between other identities within the self-concept. Researchers need to acknowledge that within society, oppressive social structures operate differently for particular groups as well as for the individual (Bowleg, 2008; Crenshaw, 1991).

Studies on identity amongst HIV positive black Africans are very scarce, particularly those living in the UK. However, one study was found which looked at diagnosis, stigma and identity. Instead of addressing traditional psychological models of identity, Flowers et al., (2006) explored the experiential and embodied links between identity, stigma and diagnosis through in-depth interviews with 30 HIV-positive black Africans. This allowed for an inductive enquiry to gain insights into the individual experiences of the participants themselves. Through the application of IPA, they revealed HIV diagnosis and treatments to be accompanied by many other challenges for HIV positive Black African people living in the UK. Although being HIV positive may lead to social exclusion for many (through stigma or HIV phobia), the degree of isolation and poverty experienced by many black African participants in their study calls for a re-contextualisation and re-consideration of the HIV experience.

They also emphasise a contrast between the UK and other African countries where treatments are not available or are too expensive to obtain. This means that an HIV diagnosis has varying meanings for people living with HIV in the UK. If a person does

not have long-term residency, it may mean a potential death sentence and a person with indefinite access to treatment has a poor prognosis involving years of chronic illness (Flowers et al., 2006). The pervasive effects of stigma associated with HIV were discussed and their results showed concerns about what a positive status meant for family and friends and people in the wider community, both in the UK and their country of origin. Therefore much of the management and negotiation involved in the participants' lives is centred on identity rather than their health and Flowers et al. (2006, p. 119) suggest "there is work to be done in helping people to manage new identities".

Rohleder and Gibson (2006) used social constructionist and psychodynamic frameworks to explore how black African women living in South Africa experience and cope with HIV stigma and their 'spoiled identity' under conditions of little support. They used discourse analysis to analyse the women's narratives and revealed social discourses around HIV as dirty, deviant, dangerous and punitive. The women drew on these discourses and internalised them to create a 'spoiled identity'. In line with Holloway and Jefferson's (2000) 'defended subject' informed by their psychodynamic framework (Joffe, 1999), many of the women struggled with these concepts of themselves and defended against the anxiety by splitting off bad representations and projecting them onto 'others' who were then presented as 'bad'. However according to Joffe (1999), what creates a 'spoiled identity' is when a person is diagnosed with HIV and is forced to incorporate the split-off aspects attributed to the 'other' and internalise the stigma attributed to them. The 'bad' identity attached to the disease is incorporated which presents a threat to the self. A strong feeling of shame may result from this identification (Rohleder & Gibson, 2006). Rohleder and Gibson's (2006) study however is rooted in a social constructionist epistemology and does not consider the individual purposive agent and avoids any recognition that these women have any internal sense of themselves.



### **1.6.1 HIV positive black African women living in the UK**

Doyle and Anderson (2005) examined the role of gender, migrant status and HIV-positive status on the lives of 62 women from sub-Saharan Africa receiving treatment from the NHS in London. They focused on life history narratives through semi-structured interviews. Their research was phenomenological in that it centred upon the participants as experts in how they have experienced HIV which provided valuable first hand, subjective knowledge about what was meaningful for them. A theme of presenting as an innocent victim arose whereby they separated their own situation from what they saw as that of the 'typical' HIV-positive woman. In terms of migrant status, many still identified strongly with their 'home' communities and considered the HIV services they received to not only keep them alive but keep them in the UK. Many of the women described physical symptoms which limited their everyday life, including fatigue, side effects and unpredictable periods of illness. This often affected their capacity to work which was cause for great distress. Feelings of depression, anxiety and uncertainty were common because the course of a potentially fatal disease cannot be accurately predicted and many have seen family and friends die from it. It was clearly understood that they would die without access to medication. Participants in their study talked about extreme hostility induced by an HIV diagnosis both 'at home' and in the UK. In general, the pressures of living with HIV led to 'biographical disruptions' (Bury, 1982) where their sense of self was radically changed as well as how they believed others viewed them. However, for many, the disease led to a re-evaluation of their lives and many things were no longer taken for granted (Doyle & Anderson, 2005).

This was reiterated in a US study of HIV-positive men and women revealing positive characteristics of coping and adjusting to an HIV diagnosis, and that endured personal distress and growth often co-exist (Littlewood, Venable, Carey & Blair, 2008). Anderson and Doyle (2004) and Ndirangu and Evans (2008) showed that African women living in the UK highly rated the medical treatment and support services they received which would be unavailable, too expensive or unattainable in their own African country. There is also a positive effect of practical coping as well as religious faith and spirituality on the quality of life and mental state of African women living with HIV in London (Dibb & Kamalesh, 2012; Doyle & Anderson, 2005).

A recent study by Dibb and Kamalesh (2012, p. 146) used IPA to explore positive adjustment to living with HIV among a sample of 12 African women living in the UK and showed that while these women experienced negative impacts of HIV (e.g. stigma, psychological distress), they also found that “their diagnosis had contributed something positive to their lives as well.” Their findings were consistent with research presented previously in that the women reconstructed the way they viewed themselves and their associated life goals by incorporating their HIV-positive status which gave new meaning to their lives. They illustrated how an HIV community played an important role in maintaining values and providing practical and emotional support in order to strengthen one’s self and others. Perhaps being part of a community is even more meaningful for African people due to the high value given to mutual care, belonging and interdependence in such cultural groups (Dibb & Kamalesh, 2012). There was the only study found to explore positive adjustment among HIV positive African women in the UK; however, further research in this area is important considering the advancements in HIV treatment (post-HAART era).

In sum, individual and social identity cannot be separated and this is particularly evident in the literature on the experiences of black Africans living with HIV in the context of identity. Enquiry into subjective experience has predominantly discussed evidence of the challenging and negative aspects of living with HIV, such as stigma, physical symptoms, uncertainty and psychological distress (Prost, Elford, Imrie, Petticrew & Hart, 2008), as well as the tough broader context of living life as an immigrant. Rohleder & Gibson (2006) maintain that individuals are exposed to powerful stigmatising discourses and may internalise these discourses however, they are also active emotional participants in their experience and dynamically engage in managing their identity and attempt to protect themselves against the anxieties associated with a ‘spoiled identity’. Their research however neglected the more positive and empowering social discourses which were found in Dibb and Kamalesh (2012). The importance of a strong sense of community was found as well as positive adjustment in black African women. It would be helpful to understand how these women and their emotional investments and cognitions interact with HIV discourses to construct their own identity.

## **1.7 Rationale for the current study**

HIV has devastated sub-Saharan Africa where infection rates are high and medical resources are scarce. Many of these Africans who now live in the UK have witnessed the shattering consequences of HIV within their community and family and this has influenced their comprehension of the disease. The principles and practices of western bio-medicine, along with the availability of HAART in the UK may be unfamiliar and “the choices that have to be made are complex and demanding” (Anderson & Doyle, 2004, p. 96). Such challenges appear to be compounded by the varying cultural backgrounds. Flowers et al., (2006) showed how the medical linearity of infection, diagnosis and treatment is clearly fragmented by social and cultural positioning. Despite the apparent need to address global inequalities, the psychosocial and service needs of black Africans living with HIV in the UK “present a relatively under-researched area within the wider HIV field” (Flowers et al., 2006, p. 118).

HIV is a chronic illness and individuals are faced with the difficult task of incorporating it into how they define themselves (Baumgartner & David, 2009). Identity is the subjective concept of oneself constructed through individual purposive agency (Thoits, 1991). However the studies which have explored HIV identity showed that many of the participants had other identities to manage, for example, being an employee, being a mother, being black, being a woman, being African. Flowers et al., (2006) suggest that researchers should consider a more pluralistic and conditional link between HIV and identity. This supports the theory of multiple identities (Thoits, 2003) and provides a rationale for learning about how HIV positive individuals make meaning, find wisdom, re-invent themselves and cultivate a positive and holistic sense of self that can help other survivors.

In Schwartz’s (2005) paper about identity research, he argues that identity research is too reliant on narrow and limiting theoretical approaches (e.g. identity theory, social identity theory) and a lack of attention to important applied social and psychological issues. He believes a more multi-dimensional model of identity which integrates personal and social aspects of the self, while making identity useful in the applied arena, such as public health, is required. Such an approach may also be more applicable to a broader range of cultural groups and research questions. As well as

public health, Schwartz (2005) believes immigration and acculturation are applied issues which the identity literature has paid little attention to. Immigration and acculturation are often stressful, considering that the immigrant must immerse him/herself in a new cultural environment and often experiences a great deal of personal change.

Research into the specific needs of HIV-positive African women sometimes results in a perception of them as a homogenous group and while they do have obvious common features (e.g. immigration policy and practices, discriminatory treatment), there is also significant diversity within this large community. Cultural, religious, economic, employment, educational, social and political differences exist both within and between African countries and these have been shown to be replicated in the UK (Anderson & Doyle, 2004). These dynamics mean that for women living with HIV throughout the UK, the meaning of an HIV diagnosis is still variable (Flowers et al., 2006). Thus, a phenomenological approach which focuses on the participants' accounts of the impact of HIV would allow for an inductive analysis of individual lived experience and capture this variability of meaning. HIV positive African women are more likely than men to access medical or support services (Doyle & Anderson, 2005). Due to the high prevalence of women from sub-Saharan Africa living with HIV in the UK (Department of Health, 2005), it is essential to better understand the dynamics of living with HIV for these women. However, there is a particular dearth of in-depth qualitative studies investigating individual lived experience within this group in the UK.

Given that identity is a dynamic system which interacts with social and interpersonal spheres in an ongoing process of identity construction (Inder et al., 2010), it seems understandable that the experience of HIV impacts on an individual's sense of identity. Whilst the importance of the impact of HIV on identity (and vice versa) has been recognised, there is a need to explore this impact and how it relates to a re-evaluation of identity which incorporates the disease. When considering chronic illness such as HIV as a very real experience for the individual but interpreted subjectively, a positivist standpoint is unsuitable because it neglects the highly variable and individualistic lived experience. A social constructionist standpoint, on the other hand, tends to lose touch with the phenomenological and experiential realities of everyday life (Crossley, 2000). Therefore, this investigation reflects a critical realist epistemology which is positioned

somewhere between positivism and social constructionism. According to Brocki and Wearden (2006) in their critical evaluation of using a phenomenological approach in health psychology, phenomenology has been employed to explore people's experiences of a range of health problems and behaviours and has been used successfully in studies of HIV (e.g., Dibb & Kamalesh, 2012; Flowers et al., 2006). It has also been "successfully used to offer theoretically-informed analyses of identity accounts in the past" (Riggs & Coyle, 2002, p. 6) (e.g. Asbring, 2001). The current study hopes to offer insights into the phenomenological experiences of HIV while also considering how HIV-positive African women come to terms with their disease and continue living with it.

### **1.7.1 Relevance to counselling psychology**

Since the introduction of HAART treatment, HIV is no longer considered a terminal illness and is now in fact likened to diabetes (Green, 2009), a chronic illness. This means that people with an HIV-positive diagnosis are better able to look toward the future. The role of HIV counselling needs to continue following the changes in the HIV dynamic and adapting itself accordingly. It has shifted from being predominantly a form of bereavement counselling to that focusing on transmission prevention and helping HIV clients to plan for the future (Aidsmap, 2011). Further research could inform advancements in the delivery, management, and promotion of health care (Haslam, Jetten, Postmes & Haslam, 2009), in particular, supportive counselling.

Counselling psychologists strive to develop flexible, reflective and critical approaches to traditional psychological theory. We acknowledge the social contexts as well as discrimination within our work and society, and endeavour to practise in ways which "empower rather than control and also demonstrate the high standards of anti-discriminatory practice appropriate to the pluralistic nature of society today" (BPS, Professional Practice Guidelines, 2008, p.2). This research aims to give voice to a marginalised group of individuals by engaging with individual subjectivity, values and beliefs. Exploring the lived experience of a chronic illness, such as HIV, would better reveal something about individual identity in the context of HIV. Counselling psychology regards the individual therapist to be an essential tool in their efficacy, emphasising the significance of the personal characteristics of the therapist. Therefore the reflexive element of a phenomenological approach is also particularly relevant to

the counselling psychology framework. Drawing upon our humanistic underpinnings, we value the need for empathy, understanding and unconditional regard for our clients (BPS, Professional Practice Guidelines, 2008). Therefore the approach to this research is dedicated to an empathic knowledge and respect for subjective experience and perception while attempting to record, interpret and reveal different accounts of black African women living with HIV in the UK. As counselling psychologists we are committed to developing models of research which meet the scientific demand for empirical enquiry while recognising the primacy of the therapeutic relationship.

## **1.8 Aims and research question**

The aim of the current study was to gain an in-depth understanding of the experience of self/identity for black African women living with HIV in the UK. The main research question was therefore:

- What are the experiences of living with HIV in the UK for black African women in the context of identity?

## **CHAPTER TWO: METHODOLOGY**

This chapter considers qualitative research in the field of psychology, provides a rationale for using interpretative phenomenological analysis (IPA), describes the participant recruitment, data collection and analysis, and outlines the steps taken to meet research quality guidelines.

### **2.1 A qualitative approach**

Research in psychology has traditionally been conceptualised from a positivist and post-positivist perspective which is comparable with the biomedical model. However, an alternative model of understanding illness was introduced through behavioral principles which gave rise to health psychology and a new model which incorporated biological, psychological and social aspects of illness resulting in the 'biopsychosocial' model (Yardley, 1997). Over time the legitimacy and adequacy of quantitative methods within psychology have been questioned. Qualitative research methods are expanding and particularly in the field of HIV and AIDS, the use and value of qualitative methodologies have been widely demonstrated (Jarman, Walsh & De Lacy, 2005).

#### **2.1.1 Rationale for qualitative research**

By rejecting hypothesis testing and structured reporting methods, and shifting the focus to lived experience of participants, qualitative approaches are useful, particularly if the research topic is complex, original or under researched. This is because unexpected findings are able to emerge (Barker, Pistrang & Elliot, 2002). Qualitative research provides rich descriptions of the phenomena under investigation via a small sample (Smith & Dunworth, 2003) and elicits information about the experience of individuals, individual conceptualisation, adoption of attitudes and incentives for change. Such methodologies pay attention to unique variation, interpersonal issues, meaning, context and culture. In suggesting a need for further qualitative studies in the field of HIV/AIDS, specifically that which attends to the positive as well as the negative aspects of HIV/AIDS, the literature reveals a need to listen to the voices of women living with HIV (Anderson & Doyle, 2004). From this perspective, participants are viewed as embodied, socio-culturally and historically situated people inhabiting an intentionally interpreted and meaningfully lived world (Smith, Flowers, & Larkin, 2009).

## **2.2 Epistemological considerations**

The chosen methodology for research needs to be in relation to critical appraisal of the literature as well as underpinned by the researcher's epistemological position in relation to the spectrum which has realism at one end and relativism at the other (Willig, 2008). Questions of meaning-making which is central to identity can be addressed from a psychosocial approach which adopts realist assumptions that the world is directly perceived as knowable facts through senses and consciousness. The literature suggests however that psychological concepts such as identity are phenomena which can be experienced by anyone depending on their subjective life experiences and an interaction between cognitive, social and biological factors. Therefore the current study is underpinned by critical realism (Bhaskar, 1975). The extreme realist approach is dismissed because it is argued that although actions and events occur in reality; these cannot be accurately described by individuals because they can only draw from their own subjective experience of reality. It was also considered impossible for me, the researcher, to produce accurate knowledge about a participant's account without imposing my own experiential perspectives on the data.

The extreme relativist position was also dismissed because an individual's account provides the researcher with access to their experience of an actual reality, not one purely constructed by language, despite the participant's account being mediated through culture, language and politics (Pilgrim & Rogers, 1997). The aim of the study is to explore how participants make sense of their experiences, not how they construct an account of their experiences. It is suggested that individuals describe their experiences of events as real to them. Critical realism however suggests that phenomena are perceived and experienced in a fluid and subjective way, depending on one's individual beliefs and expectations (Finlay, 2006). Given the phenomenological and hermeneutic foundations of IPA, it is grounded in critical realism (Finlay, 2006).

## **2.3 Interpretative phenomenological analysis (IPA)**

An interpretative phenomenological analysis (IPA) approach is particularly appropriate for investigating issues of applied psychology (Reid, Flowers & Larkin, 2005) because it reflects something of a realist ontology of the social cognitive paradigm (Flowers et



al., 2006). IPA centres explicitly on links between narrative, cognition and behaviour (Smith, 1996) which contrasts with many social constructionist approaches, for example, discourse analysis which rejects the notion of cognition (Potter & Wetherell, 1987) or grounded theory (Glaser & Strauss, 1967) which only implicitly notes the role of cognition. Although this study recognises that language and social interaction play a role in the conceptualisation of identity it is not inextricably dependent on variable and relative linguistic structures. Orthodox social constructionist approaches lose touch with the experiential realities of everyday life. Parker (1992) highlights a capacity to be reflexive as central to human agency and understanding and maintains that reflexivity is “the point of connection between the individual and the social” (Parker, 1992, p.105). It is an IPA approach which endeavours to bridge the divide between cognition and discourse (Smith & Osborn, 2008). Participants are free to share experiences which they deem to be important. This allows for data rich in detail and helps to identify key conceptual issues, all in relation to the current social landscape of black African women living with HIV in the UK (Green & Sobo, 2000).

### **2.3.1 Rationale for using IPA**

Interpretative phenomenological analysis (IPA) (e.g., Smith & Osborn, 2003; Smith, Flowers & Larkin, 2009) is a qualitative approach influenced by particular areas of philosophy of knowledge. The foremost being: phenomenology, hermeneutics and idiography. IPA was the chosen methodology for the following reasons:

- According to Smith (2004), due to its epistemological openness, IPA has been extensively used as a qualitative method for studying identity in all its complexities. This study refrains from introducing a pre-existing theoretical framework for analysing identity because, according to Smith (2004), this may impact upon information provided by the participants and impose constraints on the analysis.
- IPA is a phenomenological approach that considers phenomena as it is experienced from the first-person. In the context of IPA, phenomenology draws from Edmund Husserl’s philosophical origin of the notion of phenomenology. Husserl established the importance of careful examination of lived experience (“the things themselves”), focusing on the ways in which to identify essential

features of that experience (Smith, Flowers & Larkin, 2009, p.33). Each person perceives the world as an individual through relationships with others, objects, language and culture.

- In line with phenomenology, the current study adopts the perspective that people do have an active influence and are creatively involved in constructing their sense of meaning. This constitution of meaning is influenced by the interpretive action taking place between people (Smith, Flowers & Larkin, 2009). Meaning of life experiences, assigned by people living with HIV, could therefore be accessed through a hermeneutic process of interpretation.
- IPA employs a double hermeneutic (a two stage process), which depends on and is complicated by the researchers own beliefs and perceptions. This process involves the researcher's attempt to make sense of how the participant makes sense of their personal and social experiences (Smith, Flowers & Larkin, 2009). In practice, a degree of reflexivity is employed because the researcher carries prior experiences, preconceptions and assumptions that are influential in his or her interpretation and the experience being studied is viewed in light of their own experience.
- Idiography involves a dedication to detailed investigation of phenomena and IPA specifically calls for a small sample size in order to focus in detail on participants' individual accounts. It is not concerned with making premature generalisations about larger populations but instead focuses on reflecting detail about the perceptions and understandings of a small group (Smith, Flowers & Larkin., 2009). Smith and Osborne (2008) emphasise that IPA is particularly useful when the research focuses on complexity, process or novelty. Given the scarcity of phenomenological research giving voice to black African HIV-positive women in the UK, this fits with the aims of the current study. Also, the ideographic slant allows the reader to appreciate the phenomenon of HIV at the level of the individual as well as the wider group of participants (Flowers, et al., 2006). "Delving deeper into the particular also takes us closer to the universal" (Warnock, 1987; cited in Smith, 2004, p. 42).

- Although IPA is an approach which was initially acknowledged and developed within the field of health psychology, its function has since been demonstrated within counselling psychology research. Its philosophical considerations are somewhat consistent with that of counselling psychology (e.g., Jackson & Coyle, 2009; Riggs & Coyle, 2002; Wilkes & Milton, 2006). IPA has also been used to address other issues in HIV research (e.g., Dibbs & Kamalesh, 2012; Flowers et al., 2006; Jarman et al., 2005).

## 2.4 Reflexivity

*The remainder of this chapter will include personal accounts of reflexivity and will be illustrated using italics and the first person will be used. IPA asserts that part of the qualitative research process is an acknowledgement and presentation of the researcher's understanding and preconceptions about the research (Finlay & Gough, 2003). Through these accounts I will endeavour to provide a demonstration of how my personal interests, values, experiences and ideas have shaped the research process. This will hopefully assist the reader in evaluating my perspective and interpretation of the data, enabling the research process to be scrutinised throughout.*

*I am a thirty year old white South African woman and lived in South Africa for most of my life. I was fortunate enough to have had a privileged upbringing because my parents provided me with everything I ever needed including an education, private health care and a stable and supportive home. I always lived in affluent areas in Johannesburg amidst so much poverty, inequality and discrimination. These conflicting worlds are very apparent and felt on a daily basis and still the racial and socio-economic differences are present. My interest in HIV and AIDS was first triggered in my primary school when the mother of a friend died from the disease. During my undergraduate degree I volunteered in an HIV adoption home and before I moved to the UK I volunteered as an HIV counsellor predominantly helping HIV-positive individuals with a low socio-economic status. My experience in this capacity helped me to better understand what it might be like to be a black African with HIV in South Africa. However I still felt that there was much to learn about individual differences within this group. Now that I am living in the UK, this interest in individual difference has shifted to black Africans living in the UK and how they experience HIV,*

*in particular women because, in my experience, they were the more likely to seek help from the counselling services in South Africa.*

*My training as a counselling psychologist has exposed me to many theoretical perspectives which have challenged some previous assumptions and beliefs. I no longer agree with the principles of the positivist epistemological perspective, and I now consider knowledge and meaning to be a subjective product of experience, hence my epistemological position illustrated above. My clinical practice made me aware of how my own assumptions about what a client brings to therapy and the meaning of their narrative are relevant and cannot be ignored. My own experiences, values and beliefs cloud my perception of another individual's experience and thus my interpretation of their experience would inevitably incorporate both their meaning-making and my own. This realisation has been essential to my learning process with regard to both my clinical work and my research. Throughout the research process, I reflected in a diary to enhance my awareness such issues. Despite my enduring interest, I have not held a placement working with individuals diagnosed with HIV in the UK. For this reason I decided to develop the current study in order to gain knowledge about this topic and hopefully provide insight into how health professionals might be able to assist this particular client group in the UK.*

## **2.5 The sample**

In accordance with the requirements of IPA, purposive sampling was used to achieve as homogenous a sample as possible (Smith, Flowers & Larkin, 2009) of black African adult women with HIV. Therefore, age, gender and ethnicity of the participants were considered, as was the length of time they had been diagnosed with HIV.

*I was aware that I would only achieve as homogenous a group as possible because there are significant differences across and within African cultures. Age was only considered with regard to recruiting a sample of adults. It was decided that restricting participant criteria would not only cause pragmatic difficulties in recruitment, but may potentially limit the findings of the research, since my research aim was phenomenological in nature.*

Using the IPA framework participants consisted of a homogenous sample of five black African women with an HIV positive diagnosis. However the focus of qualitative research is the participants' perceptions of a given phenomena and because individuals possess multiple, possibly contradictory perceptions of certain issues, this is not a strictly representative sample (Flowers et al., 2006). As such, the sample was not intended to represent all HIV positive black African women living in the UK.

Two participants were from South Africa and three were from Uganda. Participant ages ranged from 38 to 65 years ( $m=48$ ). One of the participants was married, one was widowed, three were single and four had children. All had contracted HIV through heterosexual intercourse and had been diagnosed with HIV for between 10 and 22 years ( $m=14$ ). None had a current AIDS diagnosis. All were on HIV biomedical treatment. Participants had lived in the UK between 6 and 17 years ( $m=12$ ) and all had UK residency. A table of participant characteristics and demographics is presented in Appendix 8.

*As my sample was small, I wanted to ensure that I collected rich and detailed accounts from each participant. I needed to be mindful of not leading the interviews in order for it to remain participant led and a true reflection of their experience.*

### **2.5.1 Recruitment**

A purposive sampling strategy was employed (Jarman, Walsh & De Lacey, 2005). All HIV positive women receiving services from a local HIV charity in Cambridge offering support to people with an HIV positive diagnosis were informed about the study and invited to take part. An information pack was sent with an information sheet (Appendix 5) which briefly outlined the purpose of the study and what taking part would entail and a consent form (Appendix 7). However, response to this recruitment strategy was slow and people living with HIV was thought to be a challenging group to access as stigma might make it difficult for individuals to expose their HIV status.

Larger charities were generally unwilling to assist as they were inundated with requests from researchers. After only recruiting one participant after a year of trying, I decided to contact all small HIV charities in the South of England and this led to three participants who were willing to be interviewed. I later managed to recruit one more

participant from the original charity in Cambridge. Based on discussions with the charity managers, it was agreed that the participants would be given a £15 voucher for their travel expenses. Participants were invited to contact me via details given in the participant information sheet and after contact was made, further information was given, if required, and a time was arranged to meet to go through the consent form and conduct the interview.

*I felt frustrated at the lack of response in the initial stages, and restricted by my decision to investigate such a hard to reach participant group. However my persistence paid off eventually when an HIV charity in London invited me to attend a support group/conference and talk for forty minutes on my experience of HIV counselling and my research. Considering I had had little participant interest up to this point, I felt that perhaps my personal story about my interest in HIV might have influenced the women's decision to take part or perhaps it was the face to face and verbal description of my research proposal which might have resolved issues of illiteracy or time and effort required to read the initial invitation letter.*

### **2.5.2 Inclusion criteria**

The criteria for inclusion in the sample were adopted from a recent study which also used IPA to explore lived experience in HIV positive African women living in the UK (Dibb & Kamalesh, 2012). Apart from being over eighteen and diagnosed with HIV for more than one year (Jarman, Walsh & De Lacy, 2005), participants were required to have been born and raised to African parents in Africa until at least age 12 and a fluency of spoken English. As qualitative research relies heavily on language, it was considered that the richness and meaning of language might have been lost if a translator was used. As I was interested in the experience of HIV in its entirety, the onset of an AIDS diagnosis was not considered an inclusion or exclusion criterion.

## **2.6 Ethical considerations**

Ethical approval for the study was granted by the University of East London Research Ethics Committee of the School of Psychology. Supporting documentation can be seen in Appendix 3.

### **2.6.1 Informed consent**

Measures were taken to ensure informed consent to participate was achieved by providing a participant information sheet (Appendix 5). This detailed information about the study including the purpose of the research, what participation would involve, what would happen to the data, who would have access to it and where it would be stored. The information sheet was used as the basis for inviting potential participants to take part which meant that they could consider their involvement as long as they liked before contacting me.

I was aware that due to the participants reading ability and the level of English in the information sheet further verbal explanation may have been required. Therefore when I met with each potential participant, I ensured she had read and understood the information sheet and I provided her with a consent form to sign if she wished to continue and be interviewed. Two copies were signed; one given to the participant and one I kept. To prevent the participant from feeling obliged to take part, I emphasised that it is entirely her own decision and there would be no personal implications either way; in particular it would not affect her treatment or support received from the HIV charity. Participants were also told that they could withdraw from the study at any time without needing to provide a reason. All participants were able to provide informed consent so none were excluded from the study for this reason.

### **2.6.2 Confidentiality**

Participants were fully informed about confidentiality as well as its limits. Participants were asked to choose a pseudonym of her liking, which was used throughout the recorded interview and on all written documentation subsequently. They were made aware that although quotations may be used in the write up of the thesis, all identifying information would be removed or replaced with a pseudonym. They were also informed about my supervisor and other representatives from my university looking at the anonymised transcripts. Another limit of confidentiality which was expressed to each participant was that I would be obliged according to good ethical practice to share information if I thought a participant was at risk of harm. Participants were offered a copy of the final thesis for their interest.

### **2.6.3 Potential distress**

The interview covered the participant's experience of living with a life-threatening disease, which may have potentially been distressing to participants and this was addressed by providing a substantial amount of information about what taking part would involve and what topics would be considered. In this way potential participants could make an informed decision about whether or not to take part. Participants were informed about being able to request a break at any point and had the right to stop the interview or withdraw from the study at any time. Guided by my experiences of working with people in distress as well as African people living with HIV and my counselling psychology training, I endeavoured to conduct the interviews as sensitively as possible. Each of the interviews was followed by a debrief session in which I asked participants what it was like to be interviewed and how they felt after the interview. As participants were recruited from HIV support charities, sources of support, including a list of local support groups, ARV infectious disease clinics and charities was attached to the consent form. The participants also had the opportunity to return to the charity to apply for counselling with HIV trained counsellors or to attend support group meetings at the charity site.

## **2.7 Data Collection**

The study employed a cross sectional qualitative research design. Qualitative research methods such as semi-structured interviews enable a fuller, richer participant account than would a standard quantitative instrument, while also allowing the researcher flexibility in probing interesting issues that emerge (Silverman, 2000). Therefore an interview schedule was formulated to provide a heuristic framework for the interviews.

### **2.7.1 Semi-structured interviews**

Semi-structured interviews were used to explore each woman's individual experience of living with HIV. The interview schedule (Appendix 10) was developed in accordance with the study aims and was informed by relevant literature, suggestions from published guidelines (e.g., Smith & Osborn, 2003) and attending an IPA workshop. In addition, enquiries were made on presenting my topic to the charities about what they thought were important issues. It was hoped that this would prevent bias in the interview



schedule. The interview schedule followed an exploratory path (Dibb & Kamalesh, 2012) enquiring about what it was like to live with HIV, with an emphasis on personal identity and how this is impacted as a result of HIV, in what way and what transitions are made in order to learn to live with the illness. A pilot interview was conducted however only minor modifications were made to the level of language (vocabulary) in the questions. This varied depending on the participant's level of English.

The interviews started with informal conversation and completion of demographic information. Once the interview began, the questions were intended to follow a process; from more general to more specific with prompts for detail at different points. The semi-structured approach allowed me to cover issues of primary concern or interest to themselves and as a result the interviews were not rigid in sequence or in usage of all questions asked (Knight, Wykes & Hayward, 2003). As the study adopted an inductive as opposed to deductive approach, a fixed structure was avoided and questions were kept open which provided cues for participants to talk with a minimum amount of interruption or restriction by me. For example, instead of addressing factual information regarding the diagnosis, I focused on the participant's account of the impact of diagnosis. I often requested more detailed information, questioning the participant's assumptions in order to gain insight into how they perceived HIV in their everyday lives (Flowers et al., 2006).

Although participants had a good command of the English language, it was their second language and therefore in order to ensure no compromise to the validity of the data, care was taken to clarify responses if necessary and rephrase them in order to confirm that the narrative was understood. The interviews took place at the charity site where the participants had been recruited from and at the University of East London in a sound proof counselling room in the psychology department. Each interview lasted between 48 minutes and 65 minutes. Participants were asked if they had any questions (which usually led to another informal conversation) and were given a £15 voucher at the end of the interview in appreciation for their time and to cover travel expenses. All interviews were audio-recorded and transcribed verbatim by me, the researcher.

*The women shared some highly emotive and personal material during the interviews and this made me feel anxious however I was also aware that they wanted to talk about*

*experiences and emotions meaningful to them. The women were made aware prior to the interview that I was a trainee psychologist, and I wondered whether they may have used the interview context as an opportunity to be listened to and understood. I was also mindful of my own experiences of an African culture which does not traditionally employ talk therapies and I wondered whether they may have had preconceptions about what the interview would entail and what was expected of them. Some women were surprised to hear I was South African and I was unsure what this meant for them. One woman appeared to open up more after I told her and used language that implied we were the same (e.g. “we are African”). I reflected on this after the interview and wondered what this could mean about how she had perceived the interview, and me.*

## **2.8 Data Analysis**

The data was analysed using interpretative phenomenological analysis (IPA) (Smith & Osborn, 2003; Smith, Flowers & Larkin, 2009). The aim of IPA is a detailed exploration into each participant's views of the world, cognitions and meaning making and endeavours to adopt an insider's perspective (Smith, 1996) of the phenomenon being investigated. Therefore such a methodology was in accordance with the research questions to give voice to the participants. However, the term IPA recognises the dual nature (double hermeneutic) of such an analytical approach, “acknowledging that whilst IPA is committed to elucidating participants' personal perceptions of the world, the researcher achieves this through a process of interpretative activity” (Jarman, Walsh & De Lacy, 2005, p. 537) influenced by a degree of reflexivity. This too, is reflective of a critical realist perspective.

### **2.8.1 Analysis of individual transcripts**

In line with the ideographic stand point of IPA, each transcript was repeatedly read to get a general sense of participants' accounts and then sequentially analysed in-depth (Smith, Flowers & Larkin, 2009). This resulted in notes being taken about what I considered key phrases such as summaries of content, connections between different aspects of the transcript and initial interpretations. Initial annotations were made in the margin with commentary about initial thoughts on content, language use and interrogative comments (Smith, Flowers & Larkin, 2009). After re-reading each transcript, the margin on the other side was used to note emergent themes, drawing

from the transcript as well as connections in the initial commentary. Each interview transcript was analysed in this way (see Appendix 13).

### **2.8.2 Emergent themes**

Emergent themes were listed chronologically so I shifted them around to form clusters of related themes. Continual reflection and re-examination was applied to ensure that emergent themes were consistent with the dialogue and not a result of expectations shaped by my awareness of relevant literature or by my analysis of the other transcripts. Certain themes were dropped and others were expanded. Master lists of themes were then compiled for each interview, which incorporated these clusters and organised to make consistent and meaningful statements. It was only after themes had emerged from the data that theoretical concepts from the literature were called upon to enhance my psychological understanding of these themes. This led to an analysis informed by theory but not driven by it (Riggs & Coyle, 2002), (see Appendix 15).

*I needed to put aside my own beliefs and assumptions in order to remain true to the accounts of the participants. At some points I was overly concerned about doing 'justice' to the women's accounts because I struggled to discard any emergent themes. This was recorded in my reflective diary and I decided that I could later re-visit and re-evaluate the importance of some of these themes.*

### **2.8.3 Cross case analysis**

On completion of individual analyses, master lists of themes were compared from all interviews and accumulated as sub-themes within higher order categories, called 'super-ordinate themes' (Knight, Wykes & Hayward, 2003). Smith, Flowers and Larkin (2009) detail how super-ordinate themes can be identified through *abstraction* (putting like with like and developing a new name for the cluster); *subsumption* (where an emergent theme itself becomes a super-ordinate theme as it draws other related themes towards it); *polarisation* (examining transcripts for oppositional relationships); *contextualisation* (identifying the contextual or narrative elements within an analysis); *numeration* (the frequency with which a theme is supported) and *function* (themes are examined for their function).

There was a preliminary examination of relationships between the emergent super-ordinate themes which brought about a need to re-group some of the super-ordinate themes. Replicated from Knight, Wykes and Hayward's (2003) study using IPA, all themes were represented by extracts from the original text but were not chosen solely for their prevalence. 'Other factors including the richness of the particular passages which highlight the themes, and how the theme helps illuminate other aspects of the account, are also taken into account' (Smith, Jarman & Osborn, 1999, p. 226). The table of sub-themes and super-ordinate themes is shown in Table 3.2 in the results section.

## **2.9 Validity and quality**

Quality assessment of qualitative research is different from validity and reliability assessment of quantitative research and requires different assessment criteria (Barker, Pistrang & Elliott, 2002). A variety of guidelines exist for assessing validity and quality of qualitative work. However, Smith, Flowers and Larkin (2009) particularly recommend the application of Yardley's (2000) guidelines in a study using IPA and I chose to draw upon these four principles to evaluate the quality and reliability of the research. I also drew upon Smith's (2011) guidelines for evaluating the quality of IPA research and these are presented in Appendix 9.

### **2.9.1 Sensitivity to context**

Sensitivity to context should be followed from the early stages of the research process (Smith, Flowers & Larkin, 2009) and may be reached through sensitivity to pre-existing literature and theory, the socio-cultural setting of the study (Yardley, 2000) and the data obtained from the participants (Smith, Flowers & Larkin, 2009). Pre-existing empirical and theoretical literature has been outlined in the introduction where a gap in our knowledge was identified and led to the construction of a relevant research question. Sensitivity to the socio-cultural setting was achieved through depiction of the sample characteristics and by way of my method of data collection and analysis. Consideration of my reflexive role and how I might be perceived in the interaction process, as well as attention to ethical issues was maintained during all phases of the study. Sensitivity to the data was demonstrated through conducting and describing an in-depth analysis and supporting my interpretations with verbatim extracts. According to Smith, Flowers and

Larkin (2009), this allows the participants' voices to be conveyed in the study and provides an opportunity for the reader to verify the interpretations which were made.

### **2.9.2 Commitment and rigour**

Yardley (2000) emphasises an in-depth engagement with the topic as well as competence and skill in the applied method. Smith, Flowers and Larkin (2009) state that IPA assumes a degree of attentiveness to participants during data collection and careful attention to the analysis. This is evident in an interview example shown in Appendix 13 and an example audit trail of the analysis in Appendix 15. The rigour of this study may have been impacted by my being a novice researcher, as well as practical constraints such as time and the available sample. Smith (2004) however, argues the advantage of smaller samples and case studies with 10 participants at the higher end of most IPA recommendations (Smith, Jarmen & Osborn, 1999).

### **2.9.3 Transparency and coherence**

Smith, Flowers and Larkin (2009) refer to transparency as the clarity in which the research stages are written up. There needs to be coherence between the study and the underlying theoretical assumptions of the approach which is employed. I hope to have demonstrated this in the previous sections of this chapter, however in an attempt to further enhance the transparency of the analysis process, an audit trail is presented in Appendix 15. Reflexivity is considered to be an important part of research transparency (Yardley, 2000) and will be included in a detailed discussion of reflexivity in the Discussion chapter.

### **2.9.4 Impact and importance**

Yardley's (2000) final principle of impact and importance is the most fundamental in that this maintains that regardless of whether a piece of research meets the criteria of the other three principles, the real validity of a research project is in whether or not it reveals something interesting, valuable or useful. Therefore I have included consideration of the implications for practice and relevance to counselling psychology of this study both in the introduction and in the discussion chapters.

## **CHAPTER THREE: RESULTS**

### **3.1 Overview**

The interpretative phenomenological analysis (IPA) of semi-structured interviews with five HIV-positive black African women is presented in this chapter. The analysis led to the emergence of five super-ordinate themes:

- Given life but it's a struggle
- A will to survive
- Positive coping
- Negotiating a stigmatised identity
- Recognising a new me

The themes presented are but one possible construction of the phenomenon of being an African woman living with HIV in the UK for a small group of participants. In accordance with Smith, Flowers and Larkin (2009), the unearthing of themes was based upon the researcher engaging in a double hermeneutic. It is therefore acknowledged that these themes are a subjective interpretation which may have been inferred in a different way by another researcher.

This chapter will explore the super-ordinate themes as well as the relevant sub-themes through written narrative. This will be presented as select verbatim extracts from the interview transcripts although minor changes have been made to enhance readability; a description of which can be seen in Appendix 11. Whilst the five super-ordinate themes were common across the five accounts, areas of difference and divergence will also be discussed. Additional pertinent quotes for each super-ordinate theme and corresponding sub-themes are provided in Appendix 12.

### 3.2 Super-ordinate themes and related sub-themes

| <u>Super-ordinate themes</u>       | <u>Sub-themes</u>  |
|------------------------------------|--|
| Given life but it's a struggle     | "...there's a constant internal battle that goes on with myself" (Melitta) |
|                                    | Medication: Friend or foe?   |
|                                    | "Life is like a prison" (Annette)  |
|                                    | Letting go of who I was  |
| A will to survive                  | "That's strong minded is what it is, Africa is strong." (Lukiya)           |
|                                    | The value of support groups  |
|                                    | Defending against social stigma  |
| Positive coping                    | Doing vs Being   |
|                                    | "My body is shining, you can't even know I'm positive." (Soffia)           |
| Negotiating a stigmatised identity | Keeping the identity secret  |
|                                    | "We are black and we have HIV so we have both hard things" (Annette)       |
| Recognising a new me               |  |

### **3.3 Introduction to the themes**

The five super-ordinate themes provide an overview of the accounts of black African women living with HIV in the UK and how these participants attempt to make sense of their experiences. The first theme highlights participants' accounts of significant challenges created by an HIV diagnosis which extend beyond the impact of the diagnosis and encompass both internal (e.g. symptoms, internal battles) and external impacts (e.g. other people's perceptions, disruptions to everyday life) on participants' sense of identity. The following themes highlight how participants make sense of the impact of HIV on their lived experiences and sense of identity as well as how participants' sense of identity impacts on this meaning making process. How participants perceive themselves with HIV reveals something about how they experience the illness and their lived experiences of HIV reveal something about how they perceive themselves with HIV. Identity is the result of an interaction between the way participants view themselves and their construction of meaning and cognitive appraisal, real to them, and how they reflexively interpret social and embodied experience. This is reflective of the study's critical realist position. The themes suggest that this is a dynamic and fluid transitional process which entails change and adaptation in order to adjust to a life with HIV which requires reconstruction of a coherent and valued sense of identity.

Positive coping strategies emerged which enabled the women to move forward with their lives optimistically. An HIV-positive diagnosis seemed to inevitably re-shape the participants' identity as they are confronted with a new and unwanted part of their identity. However participants' accounts revealed an attempt to protect their identity by keeping their HIV-status hidden although this appeared to be complicated by participants' perception of the interplay between HIV, ethnicity and sense of identity. Despite the often adverse impacts of HIV on the lives and identities of these women, their accounts also revealed inner strength and positive growth since their HIV diagnosis which enabled them to confront the disease and move forward with their lives. Despite the challenges generated by the impact of an HIV-positive diagnosis, participants make transitions and learn to live with HIV and ultimately recognise an altered identity, highlighted in the final theme.



*Whilst I am aware that themes of a less positive nature were also evident in the data such as shame and anger and another researcher may have analysed and interpreted the data differently, I adopted a more positive analytical approach to the data. This was partly due to the lack of recent literature found taking a more optimistic stance and reporting experiences of adapting and managing to continue surviving with HIV which is now considered a chronic illness. This led me to question how black African women with HIV in the UK do manage to cope and live with the illness. Therefore my interest naturally shifted away from the more negative experiences (e.g. stigma) which have been extensively reported throughout the literature on HIV. Another motivation for approaching the data through a more positive analytic lens was led by my previous experience of working with black African women in South Africa (mentioned in chapter two). I was overwhelmed by their robust psychological functioning and processing. Despite the often devastating effects of receiving an HIV diagnosis and living with it, the women I worked with showed a remarkable determination not to give up or allow the HIV or AIDS itself to take over. In addition, perhaps considering myself to be a strong African woman played a part in my more optimistic interpretation and analysis of the women's accounts of their experiences.*

### **3.4 Theme one: Given life but it's a struggle**

This super-ordinate theme aims to capture participants' experience of the challenges they face due to internal and external influences and how these impact on living with HIV, despite the medical treatment they receive. Many of the participants talked about how the medication they were given halted the progression of the virus, enabling them to maintain their HIV status rather than progressing to the terminal prospect of it developing into AIDS. Although the medication seemed to be giving them the opportunity of life, many talked about the struggles, psychologically and physically of fully embracing wellness. This seemed important as there was also seemingly an assumption from the participants that just because they look well and are not experiencing any symptoms they perceived others as thinking that they were fine (see sub-theme 3.6.2) The sub-themes demonstrate different ways in which participants exemplify their experience of attempting to manage their health and associated changes to their life and how this impacts on participants' sense of identity. This in turn seems to have implications for their psychological wellbeing.

### 3.4.1 “...there’s a constant internal battle that goes on with myself” (Melitta)

This sub-theme highlights the difficulties the women in the study face when trying to manage life whilst at the same time also trying to control their thoughts and feelings about being out of control. This is perhaps best illustrated by Melitta’s account and her use of the term “*internal battle*”. Although well with medication, there is a sense that she is preoccupied much of the time with the difficulty of both not being able to change her health status and not being able to forget about it.

*“I’m constantly having to remind myself that I can’t change the HIV status and I also can’t be in control of it so there’s a constant internal battle that goes on with myself. I can’t put the HIV status out of my mind although I’ve been fine on the medication but I can’t put it out of my mind, it’s always there and it’s a reminder of the fact that I can’t control it”* (Melitta: lines 76-81)

So although the medication might be halting the progression of her physical decline, the medication alone does not seem to enable Melitta to fully embrace life as she is consumed by psychological and emotional struggles. “*Having to remind myself*” suggests that perhaps she is attempting to regain some control over her perceptions about HIV dominating her mind. Perhaps by doing this Melitta is trying to accept a lack of control over her HIV status.

Similarly to Melitta, Sarah talked about the difficulties that she is finding with experiencing “*joy*” in her life and that even if she does find herself experiencing some happiness in life she is unable to do so without returning to difficult feelings about the illness. There is a sense that not being “*cured*” means that she cannot live a full life and cannot be genuinely happy because she is always needing to be vigilant despite the medication making her feel “*okay*”. There seems to be an element of fear in Sarah’s account because she seems to think about life in the context of fearing the disease. There is a sense that she is reluctant to feel happy because perhaps that might detract from her vigilance which perhaps is in place to defend against her fear of the disease.

*“That means sometimes I think I am joy, but sometimes I say no, I’m not joy because if you’ve got the drugs, yeh, you take them but you aren’t cured. It’s*

*still no good, you say “What is this? I feel okay”, no, you are still sick.”* (Sarah: lines 276-279)

The extracts revealed another dilemma participants appear to face. They seem aware of the possibility of a cure for HIV in the future but at the same time they talk about having seen other people dying from the disease. This seemed to create a feeling of uncertainty for women living with HIV. In the extract below, Lukiya talked about the difficulties she faced with living, as a movement between a sense of hope and an awareness of the possibility of death. Lukiya's use of the metaphor “*sweeping back*” implies that thoughts about the illness move in and out of her mind and so her perception of the illness changes which leaves her with a sense of ongoing uncertainty regardless of how good the medication is at controlling the symptoms.

*“...you have a chronic illness it's really bad because always it's sweeping back to your mind and I don't know what is going to happen (...) at the hospital they keep saying they're going to (...) “Oh really the cure is coming?” then they say (...) and of course you see still people are dying and again they're not dying all the time because of the medication...”* (Lukiya: lines 174-180)

### **3.4.2 Medication: Friend or foe**

The extracts presented in the previous sub-theme demonstrated the psychological impact of having to struggle with living; they are apparently ‘well’ despite the possible threat of death. The medication allows participants to be well, however wellness appears to be complicated by needing to accept a lack of control, fear and uncertainty. As well as these complications, the following extracts reveal the adverse effects of the medical treatment which appear to create tension between perceiving the medication as something positive or something negative. The extract below is an example of how some participants accounted for ‘wellness’ on the medication.

*“the medication for two years kept on making me worse and worse (...) I had no hair , I was very thin, I couldn't eat, I was black like charcoal (...) so it was really quite serious.”* (Lukiya: 144-148)

Lukiya appears to consider the medication to have made her less 'well' with worse physical symptoms than before so not only does she have a life-threatening disease but she considers the experience of the medication to be "serious". This suggests a contradiction in Lukiya's experience of 'wellness'.

Although the medication prolongs life, participants seemed pre-occupied by the side effects, including pain from symptoms associated with the medication, not feeling understood and the constant reminder of their illness due to the burden of taking the medication. This was evident in the following account:

*"...I have HIV and my body is always in pain you know this disease is so bad and I have to take medications all the time and I hate it, it takes over my life, everyday I'm always worried and it's always on my mind that I must take the medication and I can't forget because it's, I'm always painful (...) it's always there. I haven't got many people to understand (...) it's just very bad, all the time."* (Annette: lines 28-36)

The language Annette uses implies a lot of pressure and a struggle to manage her illness, such as "so bad", "have to", "hate it", "worried", "I must", "I can't". Annette's account is one example of how participants spoke about the medication giving life but was at the same time a burden and prevented them from being able to live the life they would like to live ("it takes over my life"). Annette's account suggests that she experiences a sense of isolation in her experience of wellness because she feels there are few people who understand her situation.

Participants seemed to view the medication as a 'friend' or 'foe' to varying extents. Many of the women who experienced adverse effects of the medication, both physically and psychologically appeared to take the medication in order to prolong their lives and perhaps this led to a level of acceptance of a lack of choice. This was illustrated in Lukiya's account:

*"I had no choice (...) okay you won't have the quality of life you had but at least it will prolong (...) it's better than nothing."* (Lukiya: lines 159-160, 176-178)

Lukiya's extract suggests that taking the medication is better than dying so there seems to be a compromise in this position of wellness but life is not as good as it was or could be.

However one participant referred to her medication as a part of her everyday life. The extract which best elicits this, compares medication with food which could be considered part of a 'normal' routine and a requirement for survival and one which does not cause a disruption in one's life. Perhaps some participants consider their experience of medication to have less complication for their experience of wellness and therefore the medication might be considered less of a 'foe'.

*"It's not in my mind (...) except when I get a different sick (...) but now the medication it isn't in my mind, it's like in my food, I don't care, I know how I take it"* (Soffia: lines 487-493)

### **3.4.3 "Life is like a prison" (Annette)**

The first sub-theme highlighted the psychological struggles these women experience because they appear to be well but they still have a disease which threatens their life. The second revealed the presence or absence of adverse effects of the medication itself whereby some accounts drew attention to the complications associated with wellness as a result of the medication (given life). The following sub-theme addresses a different way in which participants appeared to struggle with 'living' the life that the medication has given.

Presented in this sub-theme are participants' accounts of feeling trapped due to their HIV-positive status, despite receiving medical treatment to potentially maintain the participants' physical well-being. This did not appear to be due to physical symptoms of the disease but rather due to the psychological impact of their HIV diagnosis. Some participants talked about their HIV status leaving them feeling isolated and unwilling to leave the safety of their house. Many expressed not feeling understood by anyone other than those in their support groups so when they cannot be in a safe and understanding environment, they would prefer to be alone. Annette talked about her experience of life feeling like a prison when she said:

*“life is like a prison...I have to stay at home in my bed and I get so depressed and I don’t even open my curtains (...) I don’t want to see anyone (...) I just don’t want to leave the house because if I leave the house I’m always thinking I want to be back there because it’s safe and I can be on my own because no one understands, well the people in the support group do but it’s not every day so when I’m not there I stay at home (...) when I’m sleeping I can escape because for some time I’m forgetting...”* (Annette: lines 45-47, 51-58)

Lukiya describes a similar experience when she says:

*“...you are trapped in something (...) because you are like in there (referring to her HIV-positive status) where you can’t move out, you can’t explore...”* (Lukiya: lines 340, 351-356)

Lukiya is talking about being trapped due to her HIV status and is unable to explore. In both of these accounts, there is a sense of life being like a prison because they talk about not being able to leave. It seems as though they are desperate to ‘break free’ but their HIV status is preventing them from living a ‘free’ life. Annette appears to be caught up within a destructive cycle of cognitions, emotion and behaviour and perhaps Lukiya is also and she describes this as feeling “*trapped*”.

#### **3.4.4 Letting go of who I was**

As evidenced in the previous sub-themes, participants were not only unable to rely on their health but they could no longer rely on a life without medication, and the associated effects. As noted in the previous sub-themes, this presented participants with a number of physical and psychological challenges. However a different powerful theme emerged from participants’ accounts about constraints on certain ‘normal’ activities and uncertainty about their future, despite feeling physically well most of the time.

Many of the participants experienced the impact of their HIV diagnosis through loss of certain aspects of their identity which were taken for granted before their diagnosis. In addition, some of the women expected to be in better social and economic positions than they currently found themselves in and this seemed to have a significant impact

on the way they viewed themselves. For example, some participants expected to be in a relationship, have a family and have a job, however they found themselves single, unemployed and far away from their families. They appeared to no longer be able to rely on parts of their lives which were once taken for granted. This was best illustrated in Lukiya's account of a time when she was physically unwell and how it impacted on her.

*"It impacted on me, I lost so much because when I studied in Moscow I will be finishing, I would be somebody, I will be having a good family, a good husband and my life will be, my holiday with my children and I would be having a good job, because I did finance (...) nobody is going to give you jobs when you go away all the time, you have appointments (...) you can't wake up, you are not yourself (...) sometimes you can't sleep..."* (Lukiya: lines 99-103, 332-336)

Lukiya says she *"would be somebody"* which might imply that HIV has impacted greatly on her identity because she seems to think that the disease has prevented her from acknowledging herself as a person. There is a sense that she believes she can only be somebody if she has these things in her life. This suggests that losing these parts of her life led to the loss of parts of her identity too which means she has to re-evaluate herself as a person. There is a sense that she feels distress over her incapacity to work because perhaps this part of her new identity does not fit with her former identity before her HIV diagnosis. This suggests that when coming to terms with HIV there is a need to let go of past ideas about the self that no longer fit. *"You are not yourself"* implies that she distinguishes between a former self and her current experience of herself.

A different facet to this sub-theme emerged through participants' accounts about being unable to rely on their future. As mentioned in previous sub-themes, this is due to the perpetual threat of an AIDS diagnosis which potentially leads to death. Therefore participants seemed to avoid thinking about or planning for the future in the way that they did before their HIV diagnosis. This was best illustrated by Soffia's response to the question about what her future looked like, whereby she referred to her future as something she cannot *"afford"*.

*"I've been HIV for so long I have to appreciate what God giving me now, not to start to look for others which I can't afford, I can't even look at something which I can't afford (...) for me, once I know something that I can't afford it I can't put it in my mind..."* (Soffia: lines 589-594)

There is a sense that Soffia does not own her own future (*"I can't afford"*); perhaps it belongs to "God" which might suggest she feels she has no control over her future but what she can control is how much attention she pays to it. Similarly, Lukiya's account also implies ownership however she is not necessarily referring to the future but to her life now. Her use of the words *"borrowed time"* implies that she feels she is currently living a life which she should have already lost.

*..."you are always living like on borrowed time."* (Lukiya: line 116)

In the same way that the future is unreliable, hopes and dreams can also no longer be relied upon which is evidenced in the following extract:

*"I can't control my life like I used to and I had so many plans and dreams and now it's all gone but at the same time I have life (...) many things have changed, now I think life is very short and I'm so thankful for being alive..."* (Annette: lines 180-185)

It could be argued that plans and dreams make up a part of the one's identity so Annette's extract might suggest that letting go of plans and dreams changes the way in which participants perceive themselves as well as their life. Similar to Soffia's account, there is a sense that because the future cannot be relied upon, Annette has chosen not to think about it and instead concentrates on her current life.

Living with HIV inevitably involves high levels of insecurity as the path of the disease cannot be accurately predicted and medical knowledge is partial (Doyle & Anderson, 2005). Also many of these women have seen relatives and friends die from AIDS (see 3.1.1) and they understand that without medication death is a very real threat. Therefore for these HIV-positive women, their perception of the future seemed to change which in turn altered the way they perceive the present.



*“...you don’t have so much hope for tomorrow so you just want to live the day as it comes.”* (Lukiya: lines 109-111)

Not being able to plan for the future seemed to mean that they focused more on ‘the here and now’ which may in fact suggest that not being able to rely on the future is an effective way of making the most of a ‘given life’ and ‘living’ it in the true sense of the word. Therefore, Soffia and Annette’s extracts suggest that an unreliable future might not necessarily prevent African women with an HIV-positive diagnosis from ‘living’. This is one way in which the participants’ extracts appear to contradict the super-ordinate theme and suggest that when contemplating an unreliable future, these women are given life and are better able to live.

### **3.4.5 Summary**

There appears to be some conflict when participants are confronted with HIV because they perceive themselves and are perceived by others as physically ‘well’. There also appears to be internal dilemmas between participants’ perception of the medication on the one hand providing life and on the other hand creating challenges for living and complicating the experience of ‘wellness’. Fear of psychological distress appears to lead participants to feel imprisoned whereby they do not feel secure enough to risk rejection from society or to risk having their own negative perception of themselves and the associated negative thoughts reinforced. Participants are forced to re-evaluate their identity because they experience a great amount of loss after receiving their HIV diagnosis, for example, future, plans, dreams, career and family. This theme describes parts of their identity which no longer fit. However, loss of these parts of their identity also seems to lead to a re-evaluation of life and they seem better able to embrace life in the ‘here and now’ which the medical treatment has provided.

### 3.5 Theme two: A will to survive

This super-ordinate theme captures the participants' experience of surviving and continuing to live with HIV in the UK. The previous super-ordinate theme addressed the challenges these women face, despite their access to life extending medication. Although the lived experience of HIV presents challenges, the participants' accounts also reveal cultural strength and an inner will to survive and overcome such challenges. The different ways participants demonstrate this are presented as sub-themes. Their accounts suggest that African identity is associated with strength which positively influences their ability to live with the disease. The health care these women receive as well as a sense of community within the support groups was considered a major resource in their survival and adaptation to a different cultural environment. Knowledge and understanding about HIV allowed the women to defend their HIV-positive status which appeared to be empowering. Motherhood also appeared to give these women strength and a reason to live.

#### 3.5.1 "That's strong minded is what it is, Africa is strong." (Lukiya)

This sub-theme describes accounts of the role of ethnic identity in participants' determination to survive. Participants left their home countries in search of a better life experience and health care. As mentioned previously in sub-theme 3.4.2, due to the lack of medical treatment in Africa, participants seemed to believe that if they had not been able come to the UK, they would likely have died.

*"I'm still alive (...) if I was not here the truth is I shouldn't be alive (...) I'm a survivor completely..."* (Soffia: lines 526-528)

However, in addition to the medical treatment they receive in the UK, they also talked about having a strong African identity which appears to play a pivotal role in their well being, particularly because they are away from their own community and are considered an ethnic minority group in the UK. Entrenched in this African identity seems to be a sense of strength and an innate determination to survive. When participants were asked about their ethnic identity, they all said that they were proud to be African and it was a big part of who they are. They talked about the difficulties they faced in Africa and how this has set them apart from British people because they

appear to believe that they have an inherent sense of survival which might be a result of being forced to survive unfavourable conditions and a lack of “*everything they need*”. Annette describes this in her account:

*“...I am black and I am African and it means I’m proud you know, it’s something that I am and I haven’t been something else (...) it’s like what God gives me I must continue and I must live with (...) the African people are different to the British because we don’t have everything we need and we don’t get money and so we are survivors and so maybe I’m a survivor for that, maybe I keep going forward because otherwise we die, that is maybe the same for me with this HIV...”* (Annette: lines 422-432)

Annette seems to consider her African identity to be an advantage when living with HIV. Her account suggests that perhaps she is employing adaptations from her lived experiences in Africa and making use of them in the UK in order to “*keep going forward*”. Individual experience from the participants’ past appears to shape the ways in which they view themselves and their future. Comparing her experience of survival in Africa with her experience of living with HIV suggests that surviving is not only about life and death and has something to do with ‘living’ (the challenges of which were discussed in super-ordinate theme 3.4). The will to survive seems to come from an inner strength and determination which Annette’s account would suggest is learned and rooted in her African identity. She talks about only having been one ‘self’ and accepting who she is because it is what “*God*” gave her so perhaps she also conceptualises her HIV status in this way.

Similar to Annette’s account, Lukiya talks about a “*will to live*” which she seems to consider a necessity when faced with HIV and believes it involves mental strength. Lukiya’s extract appears to exhibit a sense of determination to survive and prove to herself that she can “*make it*”, regardless of the particular life challenge. In her and Annette’s account, there seems to be a need to try to continue living, face up to the challenge and not give up and this is what Lukiya refers to as “*strong minded*” and associates with being African.

*“you have really to try hard and you prove yourself then you know you will make it (...) I try by managing whatever comes (...) that’s strong minded is what it is, Africa is strong (...) we are like that because I have a will to live (...) otherwise you find yourself you can’t do much, but in the mind, you have it there, you are strong in mind.”* (Lukiya: lines 473-474, 496, 508-518)

Annette and Lukiya talked about what it means to be African and linked mental strength and survival with their ethnic and cultural identity. This seems to have impacted on the way they experience being HIV-positive in the UK. Their accounts seem to suggest that mental strength from being African provides a will to live or survive which might have equipped participants to ‘live’ with the disease. A different way in which participants talk about the theme ‘Africa is strong’ is in terms of the African identity itself being robust. Participants seemed to identify deeply with their African heritage and culture and most did not want to become anglicised in any way regardless of citizenship. This was demonstrated powerfully in the following extract:

*“I’m African and even I’m treating my children like African, I don’t want to change them, people over here never change me. I’m African completely. I don’t want to follow their ways (...) I have a British passport but I never call myself British, I know I am African, I will never be a British citizen, never, I’m African.”* (Soffia: lines 819-823, 830-834)

Some participants’ perceptions of their ethnic and health differences appeared to reinforce their sense of identity, for example, when Melitta said:

*“...it makes me fight harder for who I am, I want people to see my ethnic values and maybe to a degree know and or somehow understand the struggles I go through as a black African in a different country and also as somebody with HIV in a different country.”* (Melitta: lines 372-376 )

Recognition of her differences and difficulties seemed to be more important to Melitta than belonging and sameness. There seems to be a sense of empowerment gained from facing up to the challenges of having HIV and she talks about her African identity in relation to this.

The significance of a robust African identity is evident in the following sub-theme in which participants talk about a sense of community and togetherness rooted in the African culture which seems to have a positive impact on the lived experience of HIV for these women. Lukiya's response to what has helped her emotionally seems to show this:

*"It is the peer support from my African people, community, I go to groups, yeah."* (Lukiya: lines 550-551)

### **3.5.2 The value of support groups**

This sub-theme reflects the role of support structures and a sense of community in living with HIV in the UK. Most of the women said they would like to live in their home country but, as mentioned previously, many believe the services and treatment provided in the UK keep them alive. A significant theme emerged from participants' accounts about the positive impact of attending support groups (also mentioned briefly in sub-theme 3.4.3) which is highlighted in Soffia's extract:

*"The doctor, the social worker, everyone where you go, whom you are talking to is nice to you, they also help me to survive. And there is support group where you are going to make you beauty your body again (...) I'm not going to die and even to take it out your mind, you see back at home you can't see those, it's so important the support group..."* (Soffia: lines 212-218)

Participants' accounts place great importance on physical appearance whereby they perceive looking well to mean they are well (see sub-theme 3.6.2). Therefore Soffia's words, *"beauty your body again"* may be referring to the value she places on the support groups because she believes that they make her feel better about herself; the way she did before her HIV diagnosis. There is a sense in this extract that Soffia is implying that if her body is physically improved, then it will be easier to *"take it out of [her] mind"* which perhaps reduces psychological distress.

As well as health care and social support, a sense of community seemed to be a valuable part of living with HIV for these women. African people often have large

families and a strong sense of community where people are closely connected and “share” and this seems to have a very supportive function. However participants seemed to feel that this is not the same in the UK.

*“African culture is very supportive and we have our big family and live together as one and we share but the African people are different to the British...”*  
(Annette: lines 426-428)

No participant currently had a husband or partner and if one had children, most had left home. The majority of their extended family lived in their home country. Therefore most of these women were on their own without family. Seeing as a sense of community seems to be important, the support groups appear to simulate community life in their African country whereby they find a sense of commonality and acceptance. This was implied when Melitta talked about potential benefits of disclosing her HIV status:

*“I might find more people that are HIV-positive that I could form a support group with and maybe try and create that kind of social support and accepting of me that I would have normally got from my African family”* (Melitta: lines 443-446)

Melitta’s account seems to suggest that the support groups might act as an alternative for kinship networks which are considered essential sources of support for these women when living in Africa.

When I asked participants about what they gain from the support groups, their accounts emphasised strength. Sarah’s account revealed, in particular, a sense of happiness and strength gained from the support groups. She talks about keeping going and how the support groups have led to further socialising and talking which are beneficial because it makes her feel strong. Her use of the adjective “great” implies closeness to her friends whereby she might be more likely to “share” her burdens which appears to be a part of her African culture (above). There is a sense that she wants to be around people which helps her to continue ‘living’ despite her illness and this is also suggested in sub-theme 3.6.1.

*“Keeping going, you’re happy with great friends, you go out, you go like you are coming here, you go and meet somebody, we go to another place, we talk, that’s a good thing because you are strong, you feel you are strong.”* (Sarah: lines 159-162)

As well as a sense of strength, Annette’s account implied that when participants are in their support groups, they experience a sense of belonging (“we” and “I don’t have to hide”) and sameness because their HIV status and ethnic identity becomes ‘the norm’ in this environment.

*“...we are all accepted and we don’t have to worry about the judgement (...) it’s the place (support group) where I can be myself and I don’t have to hide, yes maybe it’s the one place I am free (...) sometimes I wonder what I would do without these people, these other Africans with the same problems.”* (Annette: lines 253-258)

It can be argued then, that achieving a sense of commonality perhaps helps these women to feel safe enough to embrace changes to their identity, because they feel that that part of their identity is shared. This sub-theme suggests that keeping going or surviving with HIV appears to be facilitated greatly by social services offered in the UK and in particular, the support groups which provide a sense of belonging and acceptance and which lead to a feeling of strength; similar perhaps to the strength associated with participants’ African identity (sub-theme 3.5.1).

### **3.5.3 Defending against social stigma**

Being knowledgeable about HIV appears to be another way in which participants feel empowered to continue living with their disease. In particular, the way in which HIV is contracted appears to influence their identity. This may be due to the social stigma attached to the disease which seems to be an influential factor in the construction of participants’ identity. Most of the participants’ accounts emphasise that they contracted HIV from their husband or partner and they appear to conceptualise this as a more socially acceptable way of contracting a sexually transmitted infection such as HIV. Awareness of the way in which HIV was contracted seemed to provide

determination and appeared to lead to participants defending their HIV-positive status, for example, “...*they are ignorant about HIV*” (Lukiya). Soffia’s account seemed to illustrate this best when she elaborated on what helps her to be strong.

*“To keep going, you said you were strong, what helped you?” (Researcher)*

*“...the thing which is making me to be strong (...) I didn’t get it from nowhere, I get it from my husband (...) you don’t want even people to see you when you start to get sick who don’t know where you get it but for me everyone was aware about it (...) it was making very different because most of the people I didn’t hide, it doesn’t need to hide (...) I was very different (...) I was strong and to be strong it makes you to survivor...” (Soffia: lines 117-133, 692-696)*

There is a sense that Soffia is trying to ‘defend’ her HIV status because she did not get it from just ‘anywhere’; she got it from her husband which she perceives to be more socially acceptable. Perhaps Soffia is trying to engage in a more helpful way of thinking. She appears to be conceptualising her HIV status in a way that feels more acceptable and fits with her identity, perhaps as a strong, loyal wife. Her perception of society’s perception seems to play a role in shaping her identity. She implies that others will be more accepting of her HIV status if they know how she contracted the disease. Therefore she did not have to hide it, perhaps because she felt they would not judge her so her identity was not under threat. Soffia believed that this made her experience different from someone who did not contract the disease from their partner and made her “*strong*” and better equipped to ‘survive’.

Soffia’s extract was echoed in Melitta’s account because she seemed to consider HIV to be more stigmatised if there are less people with HIV and if HIV is associated with homosexuality or promiscuity, whereas it is “*less frowned upon*” when it is contracted by one’s partner. The way in which HIV was contracted seems to influence the perceptions these women have about the disease and themselves.

*“I suppose less people with it and it’s less frowned upon in Africa because I think somehow here they think it’s a gay disease or it’s a sort of (pfft) female sort of slept around whereas in Africa (pfft) usually women are getting from their husbands, it’s that sort of thing.” (Melitta: lines 209-213)*



In a similar light, the women seemed to gain a sense of empowerment from having an understanding of the disease and being 'in the know' and this too enabled them to defend against social stigma. Sarah's extract exemplifies this:

*"They think you are a crook, sleeping so many different men getting HIV, whereas you can be with one person with HIV and get it, so many people they don't know (...) I know I'm not dirty and I wasn't bad and I didn't go sleeping with other men so I'm not feeling bad about that and the people who think badly about me, well what can I do?"* (Sarah: lines 133-135, 147-150)

Sarah uses the word "crook" which suggests that she perceives promiscuity as some form of crime and she seems to think this is how others perceive her. However she defends this prejudice by providing knowledge about how the disease can be contracted which suggests that knowledge and understanding of HIV (as well as an awareness of their own circumstances) is empowering for these women and in turn, has a significant impact on the way in which they view themselves, despite the negative stigma associated with it.

When these women were in the company of other HIV-positive individuals, they appeared to feel less frustration and shame and this also suggests that being around others who have firsthand knowledge and understanding of the disease might mean that there is less conflict between participants' own identity and their perception of how society views them. Therefore there is less need to defend their HIV-positive status. A sense of commonality and acceptance from the support groups is also presented in sub-theme 3.5.2 above. This was evidenced in Annette's extract.

*"...I feel frustrated and ashamed when I hear people talking about HIV but not in the support group, it's only really with people who don't know and will think you are bad and dirty..."* (Annette: lines 222-225)

As well as reducing frustration and shame, knowledge and understanding of HIV also appeared to help participants to come to terms with their HIV-positive status which seems to be associated with a lack of knowledge about the disease. Lukiya talked

about how she feared HIV and people with HIV before her HIV diagnosis but now that she is more informed, she is less afraid. Therefore knowledge about HIV as well as how it is contracted seems to provide strength and enable these women to defend against negative social stigma and experience less fear associated with the disease.

*“...it was like something which you fear, you fear yourself and say “My God, I don’t think I can be near somebody like that”*

*“Do you still feel like that sometimes? (Researcher)*

*“No I don’t because now I have all the understanding, the knowledge, how you can get HIV, I know that but before I wasn’t.” (Lukiya: lines 282-287)*

This sub-theme suggests that knowledge about HIV, and contracting the disease in a more ‘socially acceptable’ way gives African women living with HIV in the UK a sense of empowerment which seems to alter their identity and helps them to make positive transitions and continue living with their disease.

### **3.5.4 Summary**

Ethnic and cultural identity appears to impact positively on participants lived experience of HIV because it appears to be linked with strength, survival and resilience. Previous experience (e.g. in Africa) appears to have played a part in shaping participants identity which in turn seems to influence the way in which they conceptualise their lived experience and re-evaluate their identity in the face of an HIV-positive diagnosis. Feeling valued as members of a community and support group seems to provide a sense of social belonging and acceptance. This appears to lead to a feeling of empowerment and self acceptance and seems to play a helpful role in the process of re-evaluating identity. Contracting HIV by ‘acceptable’ means and being knowledgeable about the disease seems to be empowering and enables participants to defend their HIV status in order to protect their identity from the threat of social stigma. Throughout this super-ordinate theme the extracts reveal various challenges which accompany an HIV diagnosis and these appear to be confronted by the ways participants demonstrate a will to survive and live with the disease, represented in the three sub-themes.

### 3.6 Theme three: Positive coping

The previous super-ordinate theme addressed the ways in which participants exemplify a will to survive and experience a degree of strength in order to continue living their life which the medical treatment has prolonged. However this super-ordinate theme illustrates positive coping strategies, such as, avoidance, normalising and externalising employed by participants in order to defend against their HIV-positive status in an attempt to manage the difficult emotions associated with the challenges they are faced with when living with HIV.

#### 3.6.1 Doing vs being

This sub-theme addresses ways in which some participants appeared to keep themselves pre-occupied with everyday activities which seemed to serve as a distraction from emotional difficulty brought about by the disease. In addition, some participants appeared to avoid reflecting on their lived experiences on an emotional or psychological level. In other words, the way in which some participants answer questions relating to psychological understanding of their lived experiences suggests that they adopt practical strategies to manage emotion and they focus on managing aspects of their lives which they believe they have control over; rather than their HIV-positive status which they believe they cannot control. This seemed to help participants in coping with their HIV-positive status. Annette's response to my question about coping depicts this:

*"...to be keeping busy because sometimes you can think too much and that's not good (...) it can't go away from my brain but sometimes if I'm busy it's helping me (...) appointments and support groups and the doctor and to take medication and be a good mum and be thinking about what you can control, that makes it easier (...) I can't do many things anymore, no job, no partner, no freedom, always pills and not to keep busy is bad (...) sometimes I find my life bad like I would in prison, my life before was more full and now it's empty, well (...) it's filled with different things" (Annette: lines 515-528)*

Annette's account resonates with extracts presented in super-ordinate theme 3.4 about struggling to live with an HIV-positive status. In an attempt to overcome these

difficulties, she seems to employ strategies of avoidance which could be considered functional. For example, like Melitta in sub-theme 3.4.1 there is a sense that Annette is preoccupied much of the time with the difficulty of not being in control. However she says that keeping busy, being a good mum and thinking about what she can control makes it easier. She also talks about having to take “*pills*”, “*no freedom*” (like a prison) and no longer being able to “*do things anymore*”; all of which are adverse effects revealed in the extracts in sub-theme 3.4. The language she uses suggests that keeping herself distracted from these struggles ‘frees’ her from her ‘prison’. Perhaps by keeping busy (‘doing’) Annette is avoiding old ideas about her life and her identity which no longer fit and distracting herself from reflecting (‘being’) on painful thoughts and emotions.

Although Annette’s account showed some conscious awareness of her strategy to avoid persistent thoughts about HIV dominating her mind, others were less explicit when talking about forms of coping. For example, almost all questions relating to Sarah’s internal processing and how she perceived herself, were answered in relation to food, her appearance or day-to-day activities:

*(“...do you think that’s changed the way you think about yourself?”: Researcher)*

*“Yeah (...) I’ve changed myself my way of thinking.”*

*(“How has your way of thinking changed?”: Researcher)*

*“Way of dressing up, eating, eating.”*

*(“On a day-to-day basis how do you feel emotionally?: Researcher)*

*“On a day-to-day basis (...) I do my shopping, I bake things, I do my washing, my ironing, I do my cleaning the house, I do my cooking...”*

*“I’m happy I wake up, I do my work, I go on the bus, I go to the city, the shopping, that’s it, I feel happy, just look at me, still happy.”*

*(“Oh that’s good. What other things make you happy?: Researcher)*

*“Socialise” (Sarah: lines 515-520, 188-191, 338-345)*

Sarah seems unable (or unwilling) to reflect psychologically on the impact of her lived experience of being HIV-positive. Perhaps Sarah is unwilling to talk about emotional experience with the researcher and hence consciously avoids the topics in question or

perhaps talking about external and practical aspects to her experience allows her to avoid processing difficult emotions.

By actively trying to keep busy, Sarah might be trying to cope with changes associated with her HIV-positive diagnosis and attempting to continue functioning as she did before her diagnosis. For example, Sarah's extract also resonates with sub-theme 3.4.1 where she talks about an inability to feel "joy" and here she is talking about feeling "happy" when she engages in activities which allow her to avoid thinking about her disease. Perhaps for both Sarah and Annette, avoidance is a functional form of coping with HIV.

Another extract from Sarah's account refers to her brother's acknowledgement of how she likes to go out during typical working hours, as though she has a job.

*"I can't stay in the house (...) my brother said, 'you go out as if you're working, you go in the morning, you come back at night', that's how I am."*

*("Why do you think you do that?": Researcher)*

*"So that I be strong."* (Sarah: lines 705-709)

However, this particular extract reveals a way in which actively 'doing' can also be a way of attempting to normalise living with HIV as a form of coping. Perhaps Sarah is trying to avoid practical changes to her life (e.g. no longer able to go to work) due to her diagnosis or perhaps she is trying to behave in the way she sees other people around her behaving and this allows her to feel "strong".

This sub-theme illustrates how participants actively involve themselves in activities which offer distraction from the relentless struggles of having an HIV-positive diagnosis. Avoiding and normalising appear to be positive coping strategies for these women. Counselling psychologists generally promote a sense of 'being' rather than 'doing' in order to reflect on the self and better manage psychological distress and emotion. However this sub-theme raises an interesting argument for the merit of 'doing' when 'being' is futile, unhelpful or even counterproductive.

### 3.6.2 “My body is shining, you can’t even know I’m positive.” (Soffia)

This sub-theme highlights an assumption from the participants that because they look well and are not experiencing any symptoms they are fine. There is a sense that participants believe that the better they look on the outside, the healthier they are. This seems to mean that these women use appearance as a way of coping with their HIV-positive status. However they seem to not only do this physically but mentally as well. In other words, they seem to place a lot of emphasis on how they look externally when talking about the effects of the disease and less on how they feel internally. For these women, this appears to be an effective way of managing the adverse effects of the disease which they perceive to be out of their control. Soffia exemplifies this in her extract:

*“...in Africa someone even who has money, they wouldn’t have my body (...) you can’t even see anything at all my body is shining, you can’t even know I’m positive.”*

*“...and you don’t want to look with HIV, you want to look nice in front of people...”* (Soffia: lines 245-252, 189-190)

It is as though Soffia is hiding her HIV-positive status behind her physical appearance or that she is using her physical appearance as a distraction from her HIV diagnosis. However it could be argued that this is an effective way of coping with the disease because for Soffia, her body is healthy due to the medical treatment. Perhaps it is not a form of avoiding the HIV but rather re-focusing on what is within Soffia’s control. Similar to strategies of doing vs being in sub-theme 3.6.1, perhaps focusing on appearance could also be considered a functional form of avoidance.

However some participants seemed to show an implicit awareness that their HIV-positive status was ‘masked’ by their healthy appearance. Like in sub-theme 3.4.1, this seemed to create an internal dilemma because they believe they are “*getting somewhere and making progress with this HIV*” because they look well but on the other hand they know they have HIV, which Annette refers to as “*the real me*”.

*“I sometimes feel like I’m getting somewhere and making progress with this HIV but then I go on the bus and I wonder what they are thinking and if they can*

*know I am HIV-positive but I know they can't but I feel like (...) sometimes it's like people can see me, the real me even though I don't like to disclose my HIV status to everybody..."* (Annette: lines 124-130)

Annette's healthy appearance seems to serve as a barrier between her identity and society, whose perception of her may be perceived as a threat to her identity. Her health seems to serve a protective function because it allows her to control the disclosure of her "real" identity. There is a sense that if people were able to see the "real" her, she would have to confront the illness part of her identity and perhaps the emotions associated with this are too painful.

### **3.6.3 Summary**

Keeping busy and avoiding access to emotional and psychological awareness; normalising and wanting to belong; and focusing on physical appearance and material possessions seem to be adaptive defence mechanisms for these women to avoid facing the harsh realities of a life with HIV which lead to emotional discomfort. Perhaps these women have learned that by adopting such coping strategies, they can shift the focus onto something that they can control. In addition, perhaps they are better able to come to terms with the new illness part of their identity in a way which feels more comfortable and acceptable and which better fits with pre-existing perceptions of identity.

## **3.7 Theme four: Negotiating a stigmatised identity**

In the previous super-ordinate theme, participants' accounts appear to reveal how they externalise their situation, one example is portraying an image which fits with participants' perceptions of society's expectations. This may be due to participants' fear of being rejected by society if they are different. Positively coping with HIV and its negative impact on identity potentially leads to reduced psychological distress. However, due to the stigma attached to the disease, it also means that participants potentially live according to their perception of how society views them rather than how they view themselves. This super-ordinate theme therefore highlights the ways participants' talk about their identity, behind the image they portray. However, negotiating their identity appears to be more challenging when participants are faced

with managing not only one but two stigmatised identities i.e. black African as well as HIV-positive.

### 3.7.1 Keeping the identity secret

This sub-theme highlights participants' attempts to 'hide' their identity in order to maintain an image which they perceive to be acceptable to both themselves and society. As discussed previously, managing the visibility or otherwise of their HIV status is of major concern for these women and arguably represents the most important challenge in their daily lives. Due to the stigmatising effects of the disease, participants seemed to want to be in a position to reveal their HIV status at their discretion. However, certain illnesses associated with an AIDS diagnosis (e.g. skin infections) means that disguising their disease is difficult and ultimately becomes known to others which Soffia considers a "*bad*" thing.

*"It is very, very important (appearance) and once you get skin disease (...) you know that you're HIV you can think that everyone look at you knows that you are, no one want everybody to know (...) you can't hide yourself with this thing which is bad"* (Soffia: lines 271-281, 290-291)

Soffia says that she would like to "*hide herself*" which implies that she is more comfortable keeping her identity secret and changes in her appearance jeopardises this. Similar to sub-theme 3.6.2, if participants' identity is exposed it might leave them vulnerable to their perceptions of social stigma attached to HIV which potentially creates anxiety. Participants therefore appeared to be negotiating a stigmatised identity which, if revealed, threatened their emotional and psychological well-being. This appears to leave these women feeling torn between living a "*truthful*" life and protecting themselves from the adverse effects of disclosing their HIV status. This was exemplified in Melitta's extract when she said:

*"...I'm actually not really living truthfully and that concerns me, I've got friends who actually don't know me because I haven't told them that I'm HIV positive and at the same time I don't know why that should define me but it does..."*  
*"...it's a culture that has honour and integrity and strength and honesty and those are valuable attributes that I've got from just being who I am and they are*



*very important to me and that's why I do struggle a bit with the fact that I sort of live a lie here by not telling people"*

*"...I'm more guarded because I'm often nervous that I'm going to let it slip that I'm HIV-positive in the fear of being judged..."*

*"...socially I don't allow people too close because I don't want to disclose (...) so it's easier just to have slightly more superficial friendships."* (Melitta: lines 264-268, 308-312, 480-482, 514-517)

Melitta appears to go to great lengths to protect ("*I'm more guarded*") the HIV-positive part of her identity from the threat of society's prejudice, for example, controlling her friendships. Referring to her social relationships as "*superficial*" suggests that perhaps this is how she perceives herself in society because her 'deeper', internal identity is not known to others.

Perhaps control over disclosure acts as a safety barrier between the way participants perceive themselves and how they perceive the social prejudices of the outside world, both of which may generate anxiety. Melitta's account suggests a reluctance to disclose her HIV status perhaps because this would force her to confront the illness part of her identity. When reflecting on her identity Melitta seems to experience an internal dilemma because she feels that she is "*living a lie*". Behind what she reveals to society seems to be a 'secret identity' which incorporates her HIV-positive status. Keeping this hidden however, seems to conflict with other parts of her identity such as "*honour, integrity and honesty*" which she values. The HIV-positive part of Melitta's identity appears to overshadow these other attributes because, despite their influence, she is keeping her identity secret and this seems to create an internal struggle for her.

Therefore, in support of Melitta's account, Lykiya's account reveals that participants are very careful about who they disclose their HIV-positive status to and why.

*"...disclosure, it depends, you are disclosing for who and for what (...) you have to think how they are going to take it and again you think of the impact..."*  
(Lukiya: lines 259-262)

### 3.7.2 “We are black and we have HIV so we have both hard things” (Annette)

Another way in which participants talked about negotiating a stigmatised identity was in reference to their ethnicity which is highlighted in this sub-theme. Black African is an ethnic minority group in the UK and participants seem to perceive their ethnicity to be judged in a similar way to their HIV-positive status. This is best shown in Annette’s extract below:

*“...we are black and we have HIV so we have both things, both hard things (...) the stigma here about black people is terrible, not only the HIV...”*

*“...African is beautiful and African is strong but in the world it’s discriminated like so is HIV so maybe both of those things makes a difference to how I am...”*

(Annette: 392-395, 437-440)

However, Annette’s extract reveals incongruence between participants’ ethnic identity (“beautiful”, “strong”) and the way they perceive that society views their ethnicity (stigmatised). It reveals a potential struggle for these women to maintain their identity in the face of two significant and stigmatised parts of who they are. Annette implies that both being black African and having HIV impacts on her identity. This is echoed in Melitta’s extract when she talks about the compounding effects of being an HIV-positive black African in the UK.

*“...it’s quite lonely, I suppose being black African in the UK is as lonely to a degree as being HIV-positive in the UK and doubly so if you put the two together”*

*“I’m almost a statistic (...) if I disclose the opinion’s going to be “she’s black, she’s African, obviously got AIDS” so I sort of don’t want that stereotype...”*

(Melitta: lines 354-356, 413-416)

Being black African in the UK seems to reinforce the perceived stigma attached to participants’ HIV-positive status because being black African with HIV is perceived as a stereotype which was emphasised by Melitta describing herself as a “statistic”. Similar to her extract in the previous sub-theme, there is a sense that Melitta avoids disclosing her HIV status because she fears being objectified by a societal prejudice, and even more so because she is black African. Perhaps she fears that her subjective

experience and associated identity would not be recognised or valued if she reveals her HIV-positive status, based on her black African ethnicity.

Melitta's reluctance or inability to disclose her HIV status may be what leads to her feelings of loneliness. If participants are unable to share a significant part of their identity with others, it seems inevitable that they might feel restricted socially. There is a sense from Annette and Melitta's extracts that being black African in the UK and having HIV in the UK are both challenges in themselves and these women are forced to manage the two together.

### **3.7.3 Summary**

Freedom to disclose appears to provide a protective function by allowing participants some control over how much and which parts of their identity is known to others. In addition to negotiating the part of their identity relating to HIV, these women have to negotiate the part of their identity relating to their ethnicity. Not only can black African women living in the UK feel excluded from the larger population due to their differing ethnic background, but they may also feel excluded from their own ethnic community due to their HIV status. Therefore, the potential cost of disclosure, whether intentional or not, can be significant for this participant group.

## **3.8 Theme five: Recognising a new me**

There are difficulties implicit within some of the extracts in previous themes which suggest that much of what participants are managing and negotiating within their lives centres around issues of identity rather than health *per se*. Increasingly apparent throughout the themes seems to be a continuous shift in participants' sense of identity which appears to be influenced by their self engagement with the HIV-positive part of their identity. This super-ordinate theme highlights participants' accounts of recognising how their HIV diagnosis contributed to a new identity.

Some participants' accounts suggested that they had internalised the HIV-positive part of their identity to such an extent that it now defined them. For example, when I asked Lukiya what has made her who she is today she responded:

*"Of course the diagnosis of HIV-positive, whatever I am today it's that diagnosis."*

*("Anything else?": Researcher)*

*"No" (Lukiya: lines 402-405)*

Lukiya's extract suggests that perhaps a balance is required between embracing change and avoiding it. However some participants' extracts suggest positive growth since receiving an HIV diagnosis and unlike Lukiya's extract, they suggest a complex and multi-faceted identity which has shifted. There is a sense that an HIV diagnosis reveals parts of the pre-existing identity which has not yet been consciously recognised. Participants seemed to have a strong awareness of their identity and their HIV diagnosis seemed to have a positive impact on their identity by enhancing this awareness. This was apparent in Melitta's account about her perception of the impact of HIV.

*"I think it's lifted the lid of a lot of things I knew about myself but was maybe not sure that I could express it whereas that (...) gave me the courage maybe to live up to who I actually knew I was (...) I knew that I had those traits (...) a go-getter (...) like to see the positive, I knew those things but I lived them without much thought and then when the HIV came (...) I felt like I'd lost control so I had to work really hard to get that part of me back again (...) I now realise (...) the HIV has been a huge blessing to me emotionally because I've learned so many things about myself whereas if I hadn't I would have lived in (...) oblivion to my potential (...) I would have just lived on the surface, the HIV's made me have to evaluate who I am and what I want to do with myself and my life."* (Melitta: lines 109-112, 123-130, 139-146)

There is a sense from Melitta's extract that her experience of living with HIV has enabled her to know herself better and appreciate certain qualities of her existing identity which might not have been considered if she had not been diagnosed with HIV. Her HIV status appears to have "*lifted the lid*" of her "*potential*" of which she is no longer oblivious. Perhaps Melitta's reference to control suggests that what she could still control was her will to survive. As highlighted in super-ordinate theme 3.4, HIV appears to take away a significant amount of control over participants' lives and, to a

certain extent, the medication gives back some of this control and perhaps some participants take advantage of this and “*work really hard*” to continue moving forward and maintain their identity. Therefore it appears that although participants may initially experience a lack of control after receiving their diagnosis, control can be regained and in the process participants are able to access parts of their identity which provide a sense of empowerment which may in turn reduce emotional and psychological distress, referred to as “*a huge blessing to me emotionally*”.

Melitta’s extract implies that her identity has not changed but rather it has shifted and certain parts of her self-concept have become more prominent after her HIV diagnosis. Therefore she is experiencing the same identity which has simply shifted emphasis and changed ‘shape’. However other participants talked about their identity as something “*new*” and “*changed*” after the HIV diagnosis. Like Melitta’s extract, Annette also referred to a perception of herself as different because of the “*HIV part*” of her identity; however, she talked about the HIV part of her identity leading to a new identity which is different from how she perceived herself before.

*“...in a way I’m different to how I was before because I didn’t have this HIV part of me (...) it’s like one day you have no child and then nine months later you are a mum and everything has changed, you are now a mum, life is different and you become something new”* (Annette: lines 147-162)

Annette’s extract reveals a different facet of recognising a new identity. She uses the analogy of becoming a mother to compare receiving an HIV diagnosis. This suggests that she perceives HIV as something which dramatically changes her life but is also positive and provides an opportunity for identity shift. Perhaps she feels that having HIV is not an end but rather a new beginning. Perhaps her analogy also suggests a new part to her which she now has to take care of and ensure its well-being.

### **3.8.1 Summary**

The extracts in this super-ordinate theme suggest that HIV impacts significantly on the identity of these women. Whilst the extracts acknowledged the negative impact of living with HIV, most participants spoke about positive shifts in their identity and positive transitions towards learning to live with HIV. This may not have occurred

without having acquired HIV which suggests that experiencing a life changing event such as a life threatening disease may be a catalyst which leads to a re-evaluation of the way in which identity and life is perceived.

## **CHAPTER FOUR: DISCUSSION**

### **4.1 Overview**

The aim of this study was to explore the impact of an HIV diagnosis upon a group of black African women living in the UK in terms of the influence of HIV on participants' identity. The emergent themes suggest that many of these factors are of specific importance to people from African cultures. This chapter discusses the results of this study with reference to the research question and relevance to clinical practice and in relation to the pre-existing literature outlined in chapter one. A critical evaluation of this study and opportunities for potential future research as well as implications for existing theory and practice will be discussed.

Semi structured interviews were conducted with five HIV-positive black African women. The main research question under investigation was:

- What are the experiences of living with HIV in the UK for black African women in the context of identity?

Interpretative phenomenological analysis (IPA) was employed to analyse their accounts, and five super-ordinate themes were identified. Together these five super-ordinate themes provided an overall account of what it is like to be a black African woman living with HIV in the UK.

The five themes were; given life but it's a struggle, a will to survive, positive coping, negotiating a stigmatised identity and recognising a new me. In order to suggest ways in which the findings of this study may offer insights into how health professionals might be better able to assist black African women with HIV in the UK, the results in chapter three are considered in light of psychological theory. Therefore the following sections discuss four main areas of psychological relevance of the five themes identified by the researcher as significant facets of participants' accounts of their experience. These are: control, resilience, positive adaptation and positive growth.

## 4.2 Control

The first theme 'given life but it's a struggle' reveals issues about control over physical wellness, thoughts and emotions, medication and loss. This appeared to be due to physical and emotional consequences of HIV, perceived in differing ways by participants as significant 'biographical disruptions' in continuity between the former and future self, as proposed by Bury (1982) and first described in chronic illness by Corbin and Strauss (1987). Similar to previous studies on chronic illness reviewed in chapter one, participants' varying perceptions of these biographical disruptions which have become a threat to their familiar sense of self guided their interpretation of experiences and identity construction.

All but one participant described physical (e.g. weight loss, darkening of the skin) and psychological limitations imposed by side effects associated with the HAART treatments which were talked about in terms of fear, uncertainty, isolation and non-intentional disclosure of the HIV status. As Flowers et al., (2006) argued medication itself was a constant reminder for some women of their HIV status due to the sometimes complicated drug regimes required. Appearing 'well' was important for these women because this meant their illness could be considered 'invisible' and potentially allow an element of control. This presented participants with the dilemma however of choosing to disclose an identity which would otherwise be unrecognisable to others. Clair, Beatty and MacLean (2005) referred to two strategic choices; "passing" whereby the invisible identity is hidden or "revealing" whereby it is disclosed. They propose that revealing maintains control over how others learn about a stigmatised difference as well as positively framing perception. Similarly, passing is an attempt to control information which could be stigmatised and cause emotional distress and thus; through individual life narrative participants may avoid acknowledging perceived flaws and limitations. Nonetheless, an invisible illness is dependent on the degree to which one can conceal the symptoms and associated life changes.

Some women appeared to want to protect themselves from emotional harm, although unlike in Anderson and Doyle (2004), participants did not refer to physical harm. They mainly achieved this through an avoidance strategy of adopting a more secluded



lifestyle. This seemed to be because the contrast between their situation and 'others' was often stark and painful. This changed the content and character of their social relations which perhaps impacts on their identity as it has the potential to leave these women feeling alienated and withdrawn from society. This in turn potentially reinforces this contrast and, according to their accounts, leaves them feeling "depressed" and "trapped". This was demonstrated in the sub-theme 'life is like a prison' where their perception of their threatened identity led them to experience life as a prison which was preferable to the psychological distress associated with feeling excluded by society. Further psychological concepts associated with issues of control appeared to be expressed in terms of internal dilemmas and loss as a result of biographical disruptions.

#### **4.2.1 Internal dilemmas**

Although medicine may have greatly reduced the possibility of becoming actively sick and this has offered the women a degree of control over their disease, there is still great uncertainty around the impact of the HIV. This seemed to be experienced as an internal dilemma for many of the women. Staying 'well' as a result of the medication is not necessarily 'curing' these women of the psychological impact of the illness; they talked about accompanying fears of being 'out of control' of their bodies and fears of becoming 'sick' at some stage in the future. In addition, Prost , Elford, Imrie, Petticrew and Hart (2008) reported the significance of HAART side-effects in African people's experience of HIV in the UK because it disrupts daily life.

Most of the women realised intellectually that they could live a long life with HIV however, they talked about fearing death and in particular an uncertain future ('there's a constant internal battle that goes on with myself'). This contradicts Baumgartner and David (2009) who considered the 'turning point' to be a result of medical advances instead of emotional support. Despite medical treatment, enhancement of emotional support structures appears pertinent for this participant group (sub-theme 'the value of support groups'). All participants experienced HIV in Africa where they witnessed many deaths due to unattainable treatment which also created a feeling of uncertainty because on the one hand there is life prolonging medication as well as a promise of a future cure and on the other hand participants talked about people still dying from the disease (Lukiya in sub-theme 3.4.1). There is awareness for these women that without

the medication, which has not always been certain for them, they would die and this has a significant impact on the 'healthy/sick' aspect of their identity. This is in line with Tewksbury and McGaughey's (1998) pendulum model of fluid movement between 'sick' and 'healthy' statuses in which they claim that health status is not only determined by objective medical standards but through interpretation and application of social experience and expectations. HIV service providers in the UK are therefore required to manage the apparent assurance, reliability and efficacy of Western medicine and local healthcare systems as well as the uncertainty, variability and vulnerability of heterogeneous individuals with various identities, life circumstances and cultural backgrounds.

The analysis indicates that the onset of an HIV diagnosis leads to a need to regain control, proposed by Taylor (1983) as mastery. Dibb and Kamalesh (2012) also found evidence for mastery in their theme about positive changes in behaviour however in the current study, the theme, 'a will to survive' demonstrates greater evidence for motivation for improving their perceptions of control over their lives which did involve positive coping strategies but did not necessarily mean changes in behaviour (e.g. maintaining a healthy appearance, 'doing vs being'; 'keeping the identity secret'). They all appeared to be searching for what Taylor (1983) termed meaning, mastery and self enhancement when confronted with a life-threatening event and assisting these women to achieve this would allow for an individualistic approach to re-establishing a coherent identity which Erikson (1968) believed shapes how a traumatic event (HIV) is managed.

#### **4.2.2 Experiences of loss**

Participants talked about limitation of activities which they were previously able to perform (e.g. work), reduced quality of life and uncertainty about themselves and their future ('medication: friend or foe?'; 'letting go of who I was'; 'doing vs being'). The analysis therefore revealed a lack of continuity in participants' sense of identity. Rohleder and Gibson's (2006) notion of a 'spoiled identity' or damaged self which was also demonstrated in Tsarenko and Polonsky (2011) may be reflected to some degree in the participants' accounts of loss of future self. Charmaz (1983) referred to a 'loss of self' and everything that makes life meaningful, intelligible and coherent. Disruptions of an earlier identity were often described in relation to activities prior to HIV. The

women's accounts suggested a powerful longing for their earlier life and conveyed a sense of grief over the loss of their previous identity and associated activities. Through loss of psychologically meaningful pursuits such as work, education, lifestyle and future plans and dreams for most of these women, their sense of themselves was changed radically because new parts of their identity may not fit with their former identity. This is in line with other studies on chronic illness (e.g., Lundmark & Branholm, 1996; Charmaz, 1993). Charmaz (1993) found that many social psychological situations such as those meaningful pursuits, amplify a sense of loss for individuals with a chronic illness. Unlike Charmaz (1993) however, the women in this study did not explicitly express a fear of becoming a burden to others. Not only does an HIV diagnosis impact on lived experience and identity but so do many of the psychosocial consequences of this sense of loss of who the individual once was.

Most studies referring to HIV-positive individuals and work found that most participants continued to work full-time after diagnosis due to medical treatment (e.g. Baumgartner & David, 2009). Only one of the women in this study however had continued to work which was reflected in some studies (e.g., Chinouya and Reynolds, 2001) on the impact of HAART on the lives of black Africans which showed that treatment may prevent them from finding or returning to work. Another significant loss for the women in the current study was a future including plans and dreams which could no longer be relied upon. This too impacted on their sense of identity and created a contrast between former and future self. However this did initiate a greater emphasis on the here and now and in fact led them to live for the moment which could be considered a favourable way of living. Disruption varied between participants in terms of impact and consequence. The findings in the current study suggest that these women came to terms with the possession of a new part of their identity by giving up activities or carrying them out in a different way and discovering alternative interests. This is in support of previous research (e.g., Aspring, 2001), however unlike in Aspring (2001), these women did seem to accept the consequences of having HIV.

As in Neimeyer (2006) and Mathieson and Stam (1995), the women in the current study positively adjusted by attempting to reconstruct or renegotiate a coherent and culturally situated identity by making sense of the biographical disruptions in terms of their personal history and cultural identity. This was in contrast with Rohleder and

Gibson (2006) who revealed negative damning social discourses which were internalised and although the women in their study attempted to fend off the 'spoiled identity' through subconscious defences, unlike the women in the current study, they did not reveal positive motivation or positive changes in identity. This may be due to the differences in social experience between their participants in South Africa and those in the UK. Anderson and Doyle (2005) found extreme hostility both in African 'home' countries and in the UK. This was echoed in the current findings along with a continued powerful identification with 'home' communities with some feeling trapped in the UK by the very services which keep them alive. However the current findings revealed that in the UK there appeared to be less hostility among other HIV-positive people within their own communities ('the value of support groups').

#### **4.2.3 Summary**

HIV-positive status was one of many challenges which the women in this study faced. Maintaining physical health and appearance, isolation, uncertainty, internal dilemmas, loss, stigma, protecting their identity as well as being black African were all challenges they experienced despite being given the opportunity of life through life-extending medication. Therefore such dynamics mean that the perception of an HIV diagnosis remains variable for these women. Unlike participants in Flowers' et al. (2006) all women in this study had access to treatment for the foreseeable future, however their future still remained uncertain with challenging life situations and a poor prognosis leading to a future with chronic illness. Participants expressed different degrees of coming to terms with their disease and identity re-evaluation. Despite the many challenges these women faced when living with HIV, they talked about learning how to live with the disease which they found empowering and this seemed to help them to find ways of taking control of their lives (e.g. 'a will to survive'; 'positive coping'; 'negotiating a stigmatised identity'). For example, appearance was central to these women's sense of self so having that threatened was cause for significant psychological distress. Appearing 'well' therefore provided a level of control over disclosure which was a form of protection. These findings provide support again for Taylor's (1983) notion of meaning making in order to re-establish biographical continuity which is lost following a life-threatening diagnosis. For this participant group, this appeared to be facilitated by a significant degree of resilience.

### **4.3 Resilience**

The themes 'a will to survive', 'positive coping' and 'negotiating a stigmatised identity' suggested a sense of resilience and motivation to survive the disease, reflected in Taylor's (1983) cognitive adaptation theory, and potentially regain some control which was lost after the HIV diagnosis. The findings challenge Rohleder and Gibson's (2006) sole emphasis on social discourses and neglect of personal agency in order to fully comprehend the psychosocial subject. Negative social discourses, although present, did not appear to be enough to create a spoiled identity for the women in the current study. These women did not passively accept their stigmatised identity but seemed to defend against social stigma. In contrast with other research on HIV-positive African people living in the UK (e.g., Flowers et al., 2006) and in line with Anderson and Doyle (2004, 2005), biographical disruptions were not considered entirely negative by these women due to positive insights regarding their previous life and life in general. The current findings revealed a powerful reliance on African culture and its associated perception of strength as well as resilience against a stigmatised identity.

#### **4.3.1 Strength of an African culture**

Charmaz's (1995) notion of adaptation as a response to biographical disruption whereby the altered body and illness identity is integrated into the self and the individual surrenders to the illness experience and consequences was expanded upon by Tewksbury and McGaughey's (1998) research on HIV to include three experiential phases; experience of an altered body, reformulation of philosophical frameworks and surrendering to the illness experience. The findings present ways in which participants experienced these phases. They maintain that "the individual must have a psychological, emotional and social framework to provide support and a frame for understanding" in order to surrender and survive, p.222). It is the strong cultural identity and its meaning for the women in this sample which facilitates the development of this frame, and according to Tewksbury and McGaughey (1998) with such a frame, surrendering does not mean giving up and passively allowing the disease to dominate the self but rather a positive incorporation of the experience into valued perceptions of identity and a realistic approach to the illness experience. Tewksbury and McGaughey (1998) suggested a sense of powerlessness and negative expectation, which they termed "catastrophising", as a response to

biographical disruptions among people with HIV. However, the current study found a conflicting response whereby participants expressed experiences of strength and empowerment.

As discussed in the literature on identity in African contexts, the cultural meaning of being a woman, associated with motherhood, exudes esteem and strength and perhaps this part of the participants' identity as a woman was incorporated into their sense of self. Therefore for these participants, being black African women seemed to mean being tough and resilient ('that's strong minded is what it is, Africa is strong'; 'the value of support groups'). They talked about experiencing many difficulties in their home countries which they believed made them stronger and better equipped to survive. This was one way in which these women carried forward aspects of themselves to provide biographical continuity, proposed by Corbin and Strauss (1987). Being 'strong minded' appeared to be the driving force for these women to focus on living in the face of their disease. This was different from other women with HIV because mental strength was associated with their specific ethnic and cultural identity. One participant in particular (Melitta in 3.5.1) wanted her health differences and difficulties recognised. According to Clair, Beatty and MacLean (2005) highlighting invisible illness and its associated difference is a tactic of 'revealing' referred to as 'differentiation' whereby identity is presented as equally valid and worthy of acknowledgement and altered social perception.

Although the women in the sample share certain characteristics (e.g. biology, gender relations) with HIV-positive women living in other countries, their lives are also shaped by their migrant status from some of the poorest parts in the world to one of the richest. Schwartz (2005) maintains that this is a source of added anxiety and stress which has bearing on identity. Although this was echoed in the current study, participants also appeared to positively adapt, partly due to the resilience associated with their cultural identity itself. Participants referred to their ethnic and cultural identity interchangeably because their cultural identity appeared to incorporate their ethnicity as well as their nationality. Also they referred to their 'communities' as being black African and not, for example, black Ugandan.

All participants were involved in support groups despite issues of disclosure being present. Erwin and Peters (1999) found side effects linked to HIV treatment to lead to loss of self confidence and anxiety related to disclosure. Participants however seemed to weigh up the risks of their HIV status being exposed and the potential benefits of the groups. The support groups which this group of participants attended were specifically for black minority ethnic communities (BME). Many of the women in this study were alone in the UK without family for support. The support groups however appeared to provide a strong sense of belonging and acceptance through a closely connected and supportive community which is considered essential for these women in their home countries. For this group of women, not only were the HIV services and support groups considered a major resource for their survival, but the sense of community, mutual respect and understanding within the groups was experienced as a source of strength. Therefore perhaps engagement with communal identities in these support groups facilitates re-evaluation of identity while also enhancing self perception.

According to the literature on identity and chronic illness (e.g. Charmaz, 1994) identifying which activities can be kept up, given up or carried out differently is part of the process of coming to terms with a new identity. For these women, support groups became an alternative activity and source of interest to replace earlier activities (e.g. work) which do not compromise wellbeing (i.e. less vulnerable to physical harm or emotional distress) ('the value of support groups'). Support groups offered these women new meaning to their lives and introduced them to people in similar situations. Instead of dwelling on social stigma, these women appeared to gain strength and pride from a unified cultural identity within the groups. This reflects Baumgartner and David (2009) who found that social stigma and an inability to find a suitable support group had a negative effect on the identity incorporation process. Although previous research (e.g., Tsarenko & Polonsky, 2011) has found that support groups positively influence the way HIV-positive people view themselves, Dibb and Kamalesh (2012) was the only other study on HIV-positive women in the UK found to illustrate the positive impact of community and a sense of shared cultural and ethnic identity as well as a common HIV status, within support groups. "The importance of remaining part of a community could be considered even more important for people from African cultures than Western ones, with values of mutual care, belonging and

interdependence considered highly important in these cultural groups” (Dibb & Kamalesh, 2012, p. 147). Some women however conceptualised their ethnic identity in relation to the UK as an identity threat (‘we are black and we have HIV so we have both hard things’) discussed later. Similar to Borham-Hays (2005), the current findings provide an argument against separating the mechanisms of individual identity and social identity when dealing with African contexts.

#### **4.3.2 Defending the identity**

Many of the participants’ accounts contrasted the challenges they experienced with some positive perceptions of their experience of HIV, for example extracts in, ‘a will to survive’ and ‘recognising a new me’. Joffe (1995) explained this in terms of the workings of the unconscious, such as holding onto a good, positive world when one feels their world is unhinged. Joffe’s (1999) adoption of Melanie Klein’s psychoanalytic concept of splitting objects into ‘good’ and ‘bad’ as a mechanism of defence against anxiety (evoked by identity threat) may explain what emerged from the data in sub-theme, ‘defending against social stigma’. Some women perhaps defended against perceiving themselves as ‘bad’ by projecting the ‘bad other’ onto those who were ignorant about HIV as well as those who had contracted the disease by means other than sexual intercourse with their partner. In this way the women could perceive themselves as innocent victims (‘good’), distinguishing between their circumstances and those of the ‘typical’ HIV-positive woman (‘bad’) who perhaps hold more stigma. This splitting is ironically the same strategy employed through stigmatisation (Joffe, 1995). The current analysis however suggested little evidence for total incorporation of the ‘bad’ identity attached to HIV to create a ‘spoiled identity’ (e.g., Flowers et al., 2006; Rohleder & Gibson, 2006).

According to Messner et al., (2003), not letting HIV define the individual means they are less likely to experience psychological distress. Instead of being defined by a ‘spoiled identity’, the findings reflect Holloway and Jefferson (2000) who argue against the socially constructed subject which diminishes difference and diversity in experience among individuals in similar social contexts. With their notion of ‘the defended subject’ they recognise the involvement of psychic processes to manage and minimise effects of social experience, which is similar again to Tewksbury and McGaughey (1998) mentioned above. According to their argument, although the



women in the sample internalised stigmatising perceptions of themselves, they seemed to actively defend against socially constructed threats to the self and associated anxiety. This is also in line with research by Tsarenko and Polonsky (2011) and their theory of degrees of psychological ownership of HIV.

#### **4.3.3 Summary**

Participants conveyed a sense of pride in being African in the UK and this pride was linked with resilience and hardiness which played a significant part in their perception and experience of HIV which facilitated a sense of coherence about their life and sense of identity. Participants conceptualised HIV in relation to the positive influence of cultural strength as well as a sense of community, respect and understanding in the support groups which seemed to help them feel more positive about themselves. This supports models of identity and illness in the literature review (e.g., Inder et al., 2011; Vignoles et al., 2006) which emphasise an impact of identity on illness as well as illness on identity. A chronic illness such as HIV is accompanied by much social stigma referred to in chapter one, however, participants developed a strategy of rejecting negative perceptions of others who know little about HIV experience and what it means to the individual; while incorporating the positive discourses encountered in the support groups. According to Claire, Beatty and MacLean (2005), an individual 'reveals' in order to gain social closeness as well as to share pent-up concerns and emotions to one another. Alternatively, some participants did not disclose their HIV status in an attempt to 'keep their identity secret' (3.7.1). As well as resilience, the analysis suggested that participants found ways of positively adapting to their HIV-diagnosis, reflected in Charmaz (1995).

#### **4.4 Positive adaptation**

The women in this study seemed to manage to regain control through their experience of resilience and by establishing a future way of living in society as a person with HIV. Positive adjustment among a similar participant group was specifically investigated by Dibb and Kamallesh (2012) and they too found that this occurred through positive interpretation of their situation and taking a positive stance towards managing their health and life in general. 'Surrendering' to an illness in accordance with Tewksbury and McGaughey's (1998) third phases of adaptation means internalising the lived

experience so that it is incorporated into valued perceptions of the self. Being pre-occupied and distracted (keeping busy) as well as maintaining a healthy physical appearance (externalising) meant that, in line with Mathieson and Stam (1995), participants could recover a sense of personal agency and self efficacy to resolve identity threats and avoid negative emotions and potentially achieve a desired future self.

#### **4.4.1 Keeping busy**

In an attempt to resolve some of the internal dilemmas these women experienced, some found value in new activities which kept them busy and helped to give back or provide new meaning to their lives which enabled them to re-construct their identity in relation to how they aspire to be perceived. As well as Charmaz's (1995) 'adaptation' response to biographical disruption, her notion of 'ignoring and minimising' was also evident in the women's accounts. "When HIV is minimised and ignored, it is defined as a characteristic of an individual, rather than as a defining factor of an individual's identity" (Tewksbury & McGaughey, 2008, p.224). In order not to allow HIV to define them, the women tried to preserve their former identity by maintaining some of the same activities as before and refusing to allow the disease to take control of their everyday lives. In one woman's account, this involved acting in 'auto pilot' in order to get through each day in as 'normal' a way as possible.

Ignoring and minimising was proposed as a response to biographical disruption (an alternative to adaptation) by Charmaz (1995), referred to in the section on control. Normalising was framed by Clair, Beatty and MacLean (2005) as a tactic to reveal their invisible illness so that the invisible identity is only subtly acknowledged while the severity and stigma are minimised. Royer (1998) considers normalisation to safeguard emotional stability, cope with alienation and adjust to expectations in order to incorporate the invisible identity with its limitations. Some women however seemed to live with their limitations but grieved for their former identity and keeping occupied served as a distraction from this grief. Doing rather than being was therefore more functional when coping with HIV which is in opposition to Tewksbury and McGaughey (1998) who considered minimising and ignoring to be a barrier, not a facilitator, of identity transformation. Avoidance has been shown to be an effective coping strategy in other chronic illnesses (Telford et al., 2006) and the current findings are in

opposition to Sinka, Mortimer, Evans and Morgan (2003) who showed avoidance as a coping strategy to correlate with low self esteem and depression in African people with HIV. Dibb and Kamalesh (2012) also found a positive effect of practical coping among HIV-positive African women in the UK however unlike Anderson and Doyle (2005), positive influences of religion or spirituality was not found among this participant group.

#### **4.4.2 Externalising the impact of HIV**

In an attempt to move forward with their disease and protect themselves from social stigma, the women seemed to manage the threat of having an HIV positive diagnosis with their physical appearance, perhaps with the intention of regaining control by creating an invisible illness (Clair, Beatty and MacLean, 2005). Some women were better able to cope with the impact of HIV, if it was perceived as a physical threat to their appearance rather than an emotional threat ('my body is shining, you can't even know I'm positive'). 'Externalising' the identity threat was also found in a study by Joffe (1995) among HIV-positive gay men living in the UK. The women in the current study did this in the same way as they defended against anxiety from identity threat discussed in 4.3.2. They seemed to use a splitting of their identity into a sick ('bad') past self before HAART and a healthy or 'well' ('good') current self after HAART. Rohleder & Gibson (2006) proposed that this allows the unwanted aspects of their disease to be safely situated with their past self or with those HIV-positive individuals who are visibly ill and do not look after themselves which they maintain allows the women to uphold a 'good', 'well' self. Due to having experienced a future and a former self ('letting go of who I was'), the women's accounts reflected a split between a past self which involved struggle and physically apparent symptoms and an empowered, healthy and physically "shining" future self. On the other hand, some women demonstrated self stigmatisation because they made negative assumptions about how others perceived them. However this was always talked about in the context of their appearance. If they appeared 'well' then they would be perceived in a favourable way. This reinforced their focus on looking 'well' to the outside world irrespective of their actual state of health. However this has important implications for treatment because self-stigmatisation may prevent these women from disclosing their status which is also important in halting the spread of HIV.

#### **4.4.3 Living with stigma**

Drawing on their experiences both within and outside African communities in the UK and in their home countries, these women talked about the severe hostility brought about by an HIV diagnosis. Therefore, there was a discrepancy between what the women presented to the world and how they perceived themselves and this was often experienced as an internal dilemma between inner emotion and the image and expression of emotion portrayed. Non-disclosure ('passing') was only possible however if participants' symptoms were minimally intrusive (Clair, Beatty & MacLean, 2005). According to Inder et al., (2011) achieving a unified, consistent sense of identity can be more difficult if there are contradictions between the individual's real and ideal self. Baumgartner and David (2009) maintained that issues of disclosure were woven throughout the process of incorporating HIV into the identity. The findings suggest that managing disclosure was central to these women's coping strategies and they often had to make decisions about the appropriateness and safety of disclosure in the face of changing circumstances, suggested in Clair, Beatty and MacLean (2005). Similar to findings in Anderson and Doyle (2005) and McMunn, Mwanje, Paine and Pozniak (1998), some women in the current study protected their identity by keeping their HIV status secret and creating a more separate life. It was a challenge therefore for some of them to maintain certain relationships when they considered them to be partly based on a lie. Moorhead (1999) proposes that individuals reveal an invisible identity to maintain a coherent sense of self.

Much research (e.g. Terrence Higgins Trust, 2001) suggests that stigma and discrimination obstruct disclosure and dissuade access to health or social care which in turn contributes to social exclusion. Despite this link between stigma and disclosure however, unlike in Flowers et al., (2006) these women did attend support groups. However, this may be due to the feeling of belonging due to commonality within the groups, as discussed above. Social support was important for these women when framing their psychological well being. One way in which these women protected themselves against psychological distress which in turn impacted on their experience of self was reflected in Holloway and Jefferson's (2000) notion of the 'defended subject' discussed above.

Baumgartner and Niemi (2013) found that a loss of a positive part identity such as work identity due to HIV for people in the US meant that they were burdened with what was perceived as two negative social identities, unemployed person and person with HIV. This was echoed in the current findings to some extent due to loss of former identities (e.g. work) but mainly due to the participants' black ethnic minority identity afflicting them with two stigmatised identities. In addition to negotiating the part of their identity relating to HIV, these women have to negotiate the part of their identity relating to their ethnicity (which is not invisible). The issues around living as a black African migrant suggested that HIV was but one aspect of a turbulent and altering life. Although this was also found in Anderson and Doyle's (2005) study on a similar group of women in the UK, their focus was more on migrant status than ethnic identity. Flowers et al., (2006) however referred to a pluralistic link between illness and identity in terms of being black and HIV-positive among black Africans living in the UK. Stigma research and NAT (2004) reported African participants' experiences of racism and discrimination in the UK in general as well as within black African communities. The current findings are in support of Bowleg (2008) and Smith-Lovin's (2003) argument against separating social identities as independent constructs. The women's accounts did not reveal significant impacts of HIV on spirituality, intimacy or addiction as presented in Baumgartner and Niemi's (2013) research.

#### **4.4.4 Summary**

Keeping busy and focusing on practical activities rather than the adverse effects associated with an HIV diagnosis seemed to have a positive impact on the way participants viewed themselves. Like in Aspring (2001) these women came to terms with their new identity by partly transforming their earlier identity in relation to their current situation. The current findings are in agreement with Telford et al., (2006) that reliance on concepts of acceptance versus denial when considering the lived experience of HIV is limiting and futile because the discussed coping strategies employed by these women have been shown to be adaptive responses to a life with HIV. Perhaps when considering positive coping with a chronic illness, concepts of acceptance and denial are too prescriptive and in fact they can be experienced side by side. Through resilience and positive adaptation, these women aimed to achieve their desires and future identities and this was in keeping with Vignoles' et al., (2006) concept of unconscious 'identity motives' which influence identity construction and

Taylor's (1983) notion of positive adjustment being sometimes illusory but self enhancing. One of the most important challenges for these women was managing the visibility or otherwise of their disease, not only because appearance was valued culturally but because it served a protective function against insecurity about their situation and perceived hostility towards them. Social experience (e.g. stigma) seems to interact with these women's emotional investments to re-construct their experienced identity. Not only can black African women living in the UK feel excluded from the larger population due to their differing ethnic background, but they may also feel excluded from their own ethnic community due to their HIV status. Therefore disclosure seemed to be a significant form of positive adaptation and potentially a fundamental factor in their sense of self. In addition to positive adaptation, the analysis revealed illness gains which impacted significantly on a positive sense of identity.

#### **4.5 Positive growth**

Tewksbury and McGaughey (1998) proposed a 'reformulation of philosophical frameworks' which is a progressive phase of adaptation leading to internalisation and acceptance of the disease. Participants talked about this in relation to changes in inner strength ('that's strong minded is what it is, Africa is strong'), enhanced knowledge ('defending against social stigma') hopes and dreams ('letting go of who I was'), positive coping strategies ('positive coping') and recognition of an altered self (3.8). Through their proposed phases of adaptation, women re-constructed their identities within their new philosophical frameworks. This meant a re-evaluation of and change in attitudes and behaviour in relation to the former self. Similar to Dibb and Kamalesh (2012) and some studies on other chronic illnesses (e.g. Aspring, 2001), all participants expressed new insights in terms of illness gains which led to a new and more favourable future identity ('recognising a new me'). Baumgartner and Niemi (2013) however, found systematic change in HIV-positive people in the US but it was not always positive. Some also described enhanced understanding of others, life and themselves. It appeared from the findings that these women experienced positive growth as a result of the struggles they experienced and the existential enquiry associated with them. The women appreciated everyday life more because they no longer took certain experiences for granted and had an increased sense of self awareness. There was a shift in their perspective on life which also impacted

positively on their sense of identity. The findings are in support of much of the reviewed literature on relevant theories of identity (e.g. Arpawong, 2012; Gergen and Gergen, 1988; Inder et al., 2011; Neimeyer, 2006; Whittemore, 2005).

Although no participant was entirely negative about their HIV experience, it is noteworthy that their perceptions were varied throughout the interviews with positive aspects of the experience on the one hand and hopelessness and sometimes anguish on the other. Therefore no participant was entirely positive either, despite new insights and positive growth, because they had still lost a part of their identity associated with health. Dibb and Kamalesh (2012) and Anderson and Doyle (2005) were the only two studies found to have revealed positive growth among HIV-positive African women living in the UK. Charmaz (1993) maintains that identity re-construction takes place when individuals can perceive themselves in new roles that have meaning and find renewed strength due to or in spite of the chronic illness. This was evidenced in the accounts of the women in this study because for some women the HIV enabled them to acknowledge and appreciate qualities of their existing identity more than they did before their diagnosis. Re-constructing identity was talked about in the context of regaining control of who they are which was empowering and impacted positively on their psychological wellbeing. Some women viewed their identity as 'new' and others as 'changed' however they all referred to positive growth which suggests that what is no longer a threat to these women's lives, makes them stronger.

#### **4.5.1 Summary**

The four areas of psychological importance, extrapolated from the five emergent themes in the analysis are; issues around control, an emphasis on resilience, ways of positively adapting and experience of positive growth. These four areas offer insights into additional major struggles in terms of the broader life circumstances of HIV-positive black African women living in the UK, over and above the psychological impact shared by other HIV-positive individuals. This insight has implications for clinical practice.

## **4.6 Original Contributions**

This study offers a rich contribution to an under-researched area because although a few similar studies have been presented in the literature review, none has endeavoured to answer this particular research question. Flowers et al., (2006) did not explore black African women in the UK but rather black Africans in general, Dibb and Kamalesh (2012) only investigated positive adjustment and their research was not related to identity, Rohleder and Gibson (2006) focused specifically on stigma and a 'spoiled identity' in South Africa and Doyal and Anderson (2005) examined the lives of HIV positive female migrants from Africa and did not focus on lived experience or identity. Therefore a number of the findings are novel and make an original contribution to the literature.

A unique finding from this study, which was not found in the limited studies investigating the experiences of black Africans in the UK, is the role of ethnic and cultural identity and its associated perception of strength and resilience in participants' determination to survive. There appeared to be a strong African identity which played a pivotal role in their well being, particularly because they are away from their own home community and are considered an ethnic minority group in the UK. They employ adaptations from their lived experiences in Africa and make use of them in the UK and believe that this might have better equipped them to live with the disease.

Strategies of avoidance such as doing rather than being and externalising the illness by focusing on perceptions of appearance resembles Charmaz's (1995) response to biographical disruption which she termed 'ignoring and minimising' as an alternative to the other response she termed 'adaptation'. However, unique to the findings from this study, is the suggestion that ignoring and minimising are ways in which black African women with HIV experience positive adaptation rather than being an alternative to adaptation. Participants could recover a sense of self efficacy to resolve identity threats and avoid negative emotions and potentially achieve a desired future self. For example, some women were better able to cope with the impact of HIV if it was perceived as a physical threat to their appearance rather than an emotional threat and keeping busy served as a distraction from the adverse effects associated with an HIV diagnosis and had a positive impact on the way they viewed themselves.



A sense of community and togetherness rooted in the African culture seems to have a positive impact on how these women experience their illness. This was talked about in terms of a sense of belonging and acceptance experienced through a simulated kinship and community life which was recreated within the support groups they attended. Support groups do not only serve a health care and social support function but also act as an alternative for kinship networks which are considered essential sources of support for these women in their African home countries. It appeared that engagement with communal identities facilitates re-evaluation of identity while also enhancing self perception. For this group of women, a sense of resilience, emotional support and kinship from support groups seems to underpin the 'turning point' which contradicts other studies (e.g. Baumgartner and David, 2009) which have considered the turning point to be a result of medical advances.

Black African is an ethnic minority group in the UK and participants seem to perceive their ethnicity to be judged in a similar way to their HIV status. There appears to be incongruence between participants' ethnic identity (as beautiful and strong) and the way they perceive that society views their ethnicity. A potential struggle was revealed for these women to maintain their sense of identity in the face of two significant and stigmatised parts of who they are. Not only might these women feel excluded from the larger population due to their differing ethnic background but also within their own community due to their HIV status. Although two stigmatised identities were also reported in Anderson and Doyle's (2005) study on a similar group of women in the UK, their focus was more on migrant status than ethnic identity.

Dibb and Kamalesh (2012) was the only other study found to report positive adjustment in a similar group of women in the UK. However, the main purpose of their study was to explore positive adjustment and they did not consider issues of identity. Therefore unique to the current study is that these women positively adjusted by attempting to reconstruct or renegotiate a coherent and culturally situated identity. This contradicted Rohleder and Gibson (2006) who revealed negative and damning social discourses which were internalised among a group of HIV positive African women in South Africa. The women in this study did not passively accept a stigmatised identity but seemed to be active agents in defending against social stigma. Like in Dibb and Kamalesh (2012), these women also experienced a positive shift in

their perspective on life but they also recognised how this impacted on their sense of identity.

#### **4.7 Clinical Implications**

This study provides a contribution to understanding aspects of the phenomenon of being a HIV-positive black African woman living in the UK. The findings in relation to psychological implications have been discussed which are firmly grounded in participants' actual accounts with direct quotes presented to substantiate the results (Pringle, Drummond, McLafferty & Hendry, 2011). Despite the small participant group and idiographic nature of the study which mean generalisations are not viable, Smith, Flowers and Larkin (2009, p. 38) recommends consideration for "theoretical transferability rather than empirical generalisability".

Few studies have explored lived experience of HIV-positive black African women living in the UK and although two found positive illness gains, none explored this in the context of identity. Furthermore, the cultural strength and tenacity which these women portrayed through their accounts is useful for its implications for clinical practice. Insights offered in the current findings about the relationship between HIV in an African context, identity and psychological well-being might assist health professionals working with HIV positive individuals in the UK to develop the cultural empathy necessary to assist HIV-positive African women in alleviating psychological distress. In addition, the findings are valuable for shaping formulations of the identity related difficulties that may be faced by some HIV positive African women. For example, interventions might be targeted at providing safe, non-judgemental, future focused, culturally specific conditions for exploring the client's psychological ownership, including their sense of identity. Establishing ways of regaining control, which the HIV diagnosis diminished due to the biographical disruptions, appears to have enhanced psychological ownership and assisted these women in re-evaluating their sense of identity in a positive way.

Adaptive coping strategies employed by this particular group of women may provide insight for health professionals in developing self-management programmes. Interventions which encompass an exploration of the array of impacts of HIV, in terms

of diverse and disparate experiences and consequences, on an individual's sense of identity would be valuable in helping clients to come to terms with their illness and incorporate the illness into a reconstructed sense of self. This may be a recurring process throughout the women's lives as they encounter continuous challenges associated with their disease. Counselling psychologists can employ a narrative process to assist individuals with HIV to make sense of their subjective world and experiences through integration of their past, present and future (Inder et al., 2011) with a greater sense of mastery and coherence (Taylor, 1983). This has the potential to minimise the negative impact on other meaningful identities and activities.

Psychological literature (e.g., Stanton, Revenson & Tennen, 2007) often suggests that interventions for chronic illness are too generalised and health practitioners should take an active stance in developing tailored approaches for their patients. There is a need for psychological interventions which reduce the marginalisation and stigma experienced, not only by those with HIV but those further marginalised groups such as black minority ethnic groups living with HIV in the UK. Conceptualisations and management of experiences are culturally shaped, as individuals have learned to think and act within their social context. Therefore, when developing interventions in a diverse society, it is important to consider alternative ways of making sense of illness. The current findings have demonstrated outstanding cultural resilience and strength in the face of exceptionally challenging circumstances and recognition of this, needs to form the foundation for future research and implementation of services designed to meet the needs of HIV-positive African women who live in the UK.

#### **4.7.1 Recommendations for counselling psychologists' practice**

How a black African woman with HIV perceives herself is a reflection of the interaction between who she knows herself to be and her reflexive interpretation of events. HIV is a life changing event which has a profound impact on this self perception and counselling psychologists need be sensitive to how this particular client group experience and manage their illness and what interventions might be more or less helpful. The findings suggest particular recommendations when working therapeutically with this client group.

- Participants placed great emphasis on a sense of belonging within support groups because not only do they experience a sense of belonging due to commonality of an HIV positive status but also due to their cultural and ethnic identity. Support groups provide a sense of community which resembles a valued kinship and enables these women to feel safe and accepted which might be a more appropriate therapeutic environment for counselling psychologists to help these women to embrace changes. Therefore running ethnic and cultural specific counselling groups rather than individual therapy might be more helpful for these women, particularly because certain experiences and a part of their identity is shared. Along with previous literature on HIV in African contexts (e.g., Anderson & Doyle, 2004), the analysis highlights a need for HIV culturally sensitive education within support groups with a focus on treatment and prevention because knowledge about HIV is empowering for these women and plays a significant role in the identity incorporation process.
- In order to appropriately address multiple difficulties associated with an HIV diagnosis among HIV-positive African women, an integration approach incorporating a range of service providers will be required. Perhaps working alongside other health professional would help to provide a more complete and holistic view of the clients' specific experiences and needs. There appeared to be an avoidance of psychological reflection and a tendency to externalise emotional experience such as focusing on appearance and practical activities. Perhaps individual therapy should not be the primary source of support for these women but rather a secondary tailored intervention using an appropriate therapeutic model (e.g. CBT rather than psychodynamic) appropriate for specific individual needs.
- Keeping busy and meeting with friends and having places to be in order to be physically and mentally occupied seemed to be a helpful coping strategy for these women. Therefore, perhaps implement certain interventions to promote activity or assist these women to interact and avoid isolation which makes them feel trapped. This might help them to come to terms with their illness in a way which feels more comfortable and acceptable and better fits with pre-existing

perceptions of identity. Perhaps for some clients in this group promoting doing rather than being might be more effective.

- Help clients to exchange previously valued activities for new equally valued activities and to accept an alternative definition of involvement or success and potentially adapt to another new identity as an ill but functioning individual. For example, the results indicate potential value in helping this sample group to review plans and dreams in order to make decisions about what is still important and will fit with illness related changes. The women's priorities seemed to change in terms of where they place their energy. It is therefore important for these women to let go of past ideas about themselves which no longer fit with their situation; otherwise it creates pressure to meet expectations and be someone that they can no longer be.
- The internal dilemmas these women experienced suggests that psychological support needs to be tailored more specifically for women who are managing the anxiety of 'being well' versus an uncertain future. This appeared to be an important factor in these women's lives because appearance (e.g. "the support group where you are going to make you beauty your body again") is highly valued.
- Addressing issues of disclosure might help these women to achieve more congruence between the identity which is known to the herself and the identity revealed to others and this might reduce psychological distress associated with 'living a lie'. However, counselling psychologists need to be aware of the potentially significant cost of disclosure for this particular client group due to the challenge of negotiating two stigmatised identities (black African and HIV positive).
- Consider the varying ways in which medical treatment is perceived and experienced, both physiologically and emotionally. It is not a simple matter of taking medication and continuing to live. Also, some of these women may not have had access to medical treatment of any kind in their home countries.

- Ongoing attention to one's sense of self has been shown to be important to the success of managing HIV for these women and therefore continuity of care is also important, as suggested by the value they place on support groups. Short term interventions may not be the most beneficial for this client group.

#### **4.8 Critique of the Research**

'HIV-positive black African women' is a description and representation of a group of individuals whom society perceives as homogenous and potentially stigmatised. This research however, evolved from an epistemological position which considers illness to be an experiential reality which is interpreted and perceptually modified based on an interaction between cognitive and social interpretation. Therefore the study used a small sample of women to give voice to the participants and gain insight into their subjective experience which illustrated that these identities represent distinct and varied interpretations of illness experience for these women. Therefore the findings cannot be generalised or applicable to all black African women living in the UK or elsewhere. The results however provide a basis for broader enquiry with a larger group (Giorgi, 2008) or lead to useful insights which have wider implications (Pringle, Drummond, McLafferty & Hendry, 2011). If the sample is too narrow and homogenous, judgements about transferability and links to other domains or groups might be less appropriate, however this can be overcome if limitations relating to the sample are recognised and clarified (Pringle, Drummond, McLafferty & Hendry, 2011).

The women were recruited using purposive sampling through a network of charities and therefore the findings could be significantly different for women not seeking support from an HIV charity. In addition, the women in the sample had indefinite access to the NHS and HIV treatment but for women whose immigration status is uncertain with the threat of being denied access to life extending treatments, the experience of HIV might be very different. Also, the reasons for participant participation needs to be considered because this may have a bearing on the data. As many participants were unable to work and expressed financial concerns, the £15 voucher may have been an incentive for participation. As some experiences shared in the interviews were not directly linked with the interview questions, participants may have wanted to talk about experiences relevant to their needs in an attempt to explore

and process them. Participants were aware of the researcher's position as a trainee psychologist, suggesting that perhaps the interview context was viewed as an opportunity to be listened to.

The sample consisted only of women who relied heavily on health professionals for both physical and psychological support so the findings do not reveal anything about those women who may not use such services. It is possible that the support groups and associated support programmes which participants had engaged in and most continued to attend might have affected their responses to interview questions in a more positive direction as a result of acquired inspiration and optimism. It is noteworthy that many of the women indicated that the interview experience was a beneficial opportunity to be heard and they were all willing to be contacted again and expressed an interest in reading the completed research thesis. In addition, all participants lived in a metropolitan area, either London or Cambridge so the voices of those living in more remote areas of the country were underrepresented in this study.

It is acknowledged that the interview schedule may have had an effect on participants' accounts as well as the emerging themes. However the researcher made every effort to avoid leading questions and to adapt the interview schedule in a flexible manner, using additional prompts and formulated questions in response to participants' narratives. In addition, participants were offered an opportunity to elaborate or comment on anything they considered not to have been addressed. This potentially allowed for unanticipated material to emerge. Research quality and validity have been discussed in chapter two with reference to Yardley's (2000) guidelines. Validity was pursued by highlighting, in this discussion chapter, interesting, relevant and useful information which challenges and enhances the existing literature.

The women made sense of themselves as individuals with HIV which the findings suggest is determined 'through' rather than 'by' their interactions with and perceptions of others. IPA was therefore particularly suitable in this research because it recognises the social and psychological processes of identity re-construction as two directional and variable. Also, the rich in-depth data generated may not have been acquired from a larger sample size, thus again the recommendation of IPA to recruit a small sample size was appropriate. This is also in keeping with counselling psychology principles

which strive to develop current models of practice and enquiry which take into account subjective first-hand accounts as valid in their own terms (BPS, Professional Practice Guidelines, 2008, p.1). The interpretative and hermeneutic aspects of IPA captured examples of convergence and divergence, in contrast to Giorgi (2008) who recommends focusing solely on commonalities (Smith, Flowers & Larkin, 2009) which does not expose individual difference. However, the use of an IPA approach did not allow for rich engagement with discourse which may have revealed relevant issues of social power, morality and inequality. This is therefore a potential avenue for further research.

In line with an idiographic approach advocated in IPA, the focus is on participants' cognitive, linguistic, affective and physical being (Pringle, Drummond, McLafferty & Hendry, 2011). Literature has proposed that an individual's first language is "the language system that holds the fullest complement of sensational, affective and cognitive elements related to early experience" (Perez-Foster, 1998, p. 9, in Tribe & Keefe, 2009, p. 416). If particular thoughts and feelings are enmeshed in language and can be defended against when speaking a foreign language, it is necessary to consider the impact of this when interviewing African women in their second language because it may be that emotional reactions and responses are 'lost in translation'. For example, understanding of 'identity' may be different or less important in the African culture. As a worthwhile avenue for further research, these women could be interviewed in their first language.

Unlike descriptive phenomenology (Giorgi, 2008), IPA highlights the importance of the researcher's position within the study. However this can threaten the rigour of the data required by phenomenology. This study was conducted and analysed by one white South African researcher which runs the risk of representing a simplistic interpretation, influenced by differences in experience and interpretation between the researcher and black African women in the UK. Therefore a paper trail in Appendix 15 has been provided in the hope of portraying a coherent and legitimate interpretation which is attentive to the words of the participants (Pringle, Drummond, McLafferty & Hendry, 2011). In addition, my research supervisor and one colleague read my interpretations of the data at different stages of the analysis which helped to achieve reliability. Unintentionally throughout the research process, personal interest may have been



conveyed through verbal and non-verbal nuances during the interview, for example, an agreement or disagreement or parts of the participants' accounts which the researcher chose to explore, whilst potentially ignoring others. An attempt to address such issues was made through regular entries in a reflective diary, explicitly noting areas of interest or personal reflection in order to achieve as neutral a position as possible in the research process.

*Considering my own position in the research (presented in italics in chapter two) as well as being a white South African woman, my interpretation of the phenomenological meaning of the experiences of these women may have been influenced by common cultural understandings or lack thereof due to variation in cultural meaning. For example, although I too am African, there was a distinct difference in their perception of my cultural identity and theirs. I wondered how my own experience of being African and my cultural and ethnic position within South Africa with the associated beliefs and values, as well as my experience of now living in the UK might impact on the data. Furthermore, I was aware of the potential influence of my previous experience or relevant knowledge gained from my HIV counselling in South Africa on the analysis.*

Considering the positive growth and adaptive focus of the current findings, this area of research might benefit from further investigation of the perceived value of specific forms of recovery and growth for African people living with HIV. Another avenue for future research is an investigation into the perspectives of service providers and health professionals working with HIV-positive black Africans. Furthermore, an exploration of what it might be like for HIV-positive African men living in the UK could add to this under researched area or provide interesting results for comparison because they are positioned differently within society.

## CONCLUSIONS

The primary aim of this study was to gain an in-depth understanding of the experiences of HIV-positive women living in the UK in the context of identity and how they make transitions and learn to live with the disease. The role of cultural identity was also explored. The results were found to be somewhat consistent with existing literature on the lived experiences of HIV and theory of identity. However, as far as the researcher was aware, this specific investigation with this specific participant group had not been carried out before so findings were discussed in relation to literature pertaining to either other chronic illnesses, other participant groups or studies conducted in other countries.

The process of constructing a sense of identity in the face of a chronic illness such as HIV is ongoing. Even if an experience is perceived as creating negative changes to the self, it is possible that this might change again in a more empowering direction, for example, perceiving the self as more resilient and strong or being more tolerant towards others or changing approaches to life. Therefore identity is constantly re-evaluated and re-constructed as a 'work in progress'. Most women in the sample came to terms with a new part of their identity, to varying degrees, by giving up activities, performing them in a different way or engaging in alternative activities. Therefore identity appeared to be partially reconstructed by partly renegotiating their former identity in relation to their current situation. The illness experience for these women paradoxically consisted of struggles and illness gains.

These women found value in living and observed their lives in an integrative, dynamic and constructive way by 'surrendering' to the disease. A new experience of the self occurred through responses to biographical disruptions, internal dilemmas and loss. In this group of women, their sense of self changed relative to their HIV-positive status. However the findings provide insight into their ability to develop strategies to adapt and live positively with HIV. Not only does HIV have an impact on these women's sense of identity but it also facilitates the possession of a new reconstructed identity.

For these women, the new identity comprised both healthy and sick aspects of the self which included the self and social environment which suggests that they needed to

actively negotiate being a part of a world of health, despite the disease. HIV did not remove these women from their society but rather reinforced their position within it. These women appeared to be striving to survive HIV with the access to HAART in the UK but not necessarily within an environment or circumstances of their choice, because they all still identified strongly with their 'home' communities and 'preferred' life in Africa. This is a significant paradoxical reality in a world where global inequalities affect access to HIV treatment and female migration to developed countries is increasing.

Seeing as these women expressed a struggle to negotiate two stigmatised identities; black African and HIV, support groups in the UK may be more than just a form of support for the disease itself but also for other parts of the individual's identity which HIV impacts on. Being around people of similar cultural backgrounds reassured these women that they are not alone and can draw upon cultural strength to continue living and re-construct a new identity despite the disease. They did not appear to allow the HIV part of their identity to dominate their sense of identity and perhaps this was influenced by their perception of acceptance and belonging amongst a common cultural identity associated with strength.

Overall, it is hoped that this study has provided an in-depth idiographic approach to the exploration of what it is like for black African women living with HIV in the UK, while highlighting unique experiences and perceptions which may be of relevance to clinical practice. Furthermore, it is hoped that this research has presented the reader with a demonstration that this particular group of HIV-positive African women are not defined by their disease but rather by a cultural strength which is best illustrated by the words of one participant who said; "What does not kill me, makes me stronger".

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## APPENDICES

### ***Appendix 1: Response from 'Africare Trust' re participant recruitment***

From: **Kulaba Judith** (kulabajuflo2001@yahoo.com)  
Sent: 15 April 2013 01:58:19 PM  
To: Emily Tait  
amandaamito@afRICANCARER.org (amandaamito@afRICANCARER.org);  
Cc: judithkula@afRICANCARER.org ([judithkula@afRICANCARER.org](mailto:judithkula@afRICANCARER.org))

Dear Emily,

I have just read your email. I would like to inform you that Africare normally hold support group Events at the end of every month.

Our service users do attend these events. One for this month is due saturday the 27th April 2013 at white city community centre. W12 7QT.  
Time: 1 pm- 4pm.

If you can come on that day, then i can arrange 10min or more if needed for you to talk to the service users about your research so they can ask you any questions they have. From there, those who are comfortable with participating in the research will give their consent and you can arrange the dates for the interview.

Please confirm if you will be able to make it so as to fix time for you. Thanks.

Judith Kulabako  
AFRICARE

**Appendix 2: Researcher's time slot for presentation at the ASHN  
Conference – 27.04.13**

**AFRICAN SEXUAL HEALTH NETWORK**

Blood pressure checks, Welfare reforms, Reflexology

**PROGRAM**

| <b>TIME</b>           | <b>ITEM</b>   |
|-----------------------|---|
| <b>12.30 - 1.00PM</b> | <b>Arrival and Registration<br/>Welcome and introduction</b>  |
| <b>1.00 - 1.30PM</b>  | <b>Blood pressure talk by Barry Coppock<br/>(Stroke Association)<br/>Blood pressure Checks – on going till last<br/>check</b> |
| <b>1.30 - 2.30PM</b>  | <b>Presentation by Richard Chilton<br/>(H &amp; F citizens Advice bureau)<br/>- Welfare Reform</b>                            |
| <b>2.30 - 3.05PM</b>  | <b>Presentation by Azizat Adefesobi (Africare)<br/>Reflexology</b>  |
| <b>3.05 – 3.45 PM</b> | <b>Emily Tait (University of East London)<br/>-African women HIV Research</b>   |
| <b>3.45- 4.30 PM</b>  | <b>Refreshments and networking</b>  |

### **Appendix 3: Ethical approval**

#### **ETHICAL PRACTICE CHECKLIST (Professional Doctorates)**

**SUPERVISOR:** Kendra Gilbert

**ASSESSOR:** James Walsh

**STUDENT:** Emily Tait  
14/08/2012

**DATE (sent to assessor):**

**Proposed research topic:** An investigation into the lived experiences of HIV positive African women living in the UK.

**Course:** Prof Doc Counselling

- |  |     |
|--|-----|
| 1. Will free and informed consent of participants be obtained?   | YES |
| 2. If there is any deception is it justified?  | N/A |
| 3. Will information obtained remain confidential?  | YES |
| 4. Will participants be made aware of their right to withdraw at any time?   | YES |
| 5. Will participants be adequately debriefed?  | YES |
| 6. If this study involves observation does it respect participants' privacy?   | NA  |
| 7. If the proposal involves participants whose free and informed consent may be in question (e.g. for reasons of age, mental or emotional incapacity), are they treated ethically? | NA  |
| 8. Is procedure that might cause distress to participants ethical?   | YES |
| 9. If there are inducements to take part in the project is this ethical?   | YES |
| 10. If there are any other ethical issues involved, are they a problem?  | NA  |

#### **APPROVED**

|  |                                  |
|--|----------------------------------|
|  | YES, PENDING MINOR<br>CONDITIONS |
|--|----------------------------------|

**MINOR CONDITIONS:** That the supervisor be shown a copy of the written permission granted by the Charity in question to approach participants – this should be done before data are collected.

#### **REASONS FOR NON APPROVAL:**

Assessor initials: JW Date: 27<sup>th</sup> August 2012



## RESEARCHER RISK ASSESSMENT CHECKLIST (BSc/MSc/MA)

**SUPERVISOR:** Kendra Gilbert

**ASSESSOR:** James Walsh

**STUDENT:** Emily Tait  
14/08/2012

**DATE (sent to assessor):**

**Proposed research topic:** An investigation into the lived experiences of HIV positive African women living in the UK.

**Course:** Prof Doc Counselling

Would the proposed project expose the researcher to any of the following kinds of hazard?

- |    |  |     |
|----|--|-----|
| 1  | Emotional                              | YES |
| 2. | Physical                               | NO  |
| 3. | Other<br>(e.g. health & safety issues) | NO  |

If you've answered YES to any of the above please estimate the chance of the researcher being harmed as:                      LOW

### APPROVED

|     |  |
|-----|--|
| YES |  |
|-----|--|

### MINOR CONDITIONS:

### REASONS FOR NON APPROVAL:

Assessor initials:     **JW**     Date: 27<sup>th</sup> August 2012

**SCHOOL OF PSYCHOLOGY**

Dean: Professor Mark N. O. Davies, PhD, CPsychol, CBiol.

**UEL**  
University of  
East London

[www.uel.ac.uk](http://www.uel.ac.uk)

**School of Psychology**  
**Professional Doctorate Programmes**

To Whom It May Concern:

This is to confirm that the Professional Doctorate candidate named in the attached ethics approval is conducting research as part of the requirements of the Professional Doctorate programme on which he/she is enrolled.

The Research Ethics Committee of the School of Psychology, University of East London, has approved this candidate's research ethics application and he/she is therefore covered by the University's indemnity insurance policy while conducting the research. This policy should normally cover for any untoward event. The University does not offer 'no fault' cover, so in the event of an untoward occurrence leading to a claim against the institution, the claimant would be obliged to bring an action against the University and seek compensation through the courts.

As the candidate is a student of the University of East London, the University will act as the sponsor of his/her research. UEL will also fund expenses arising from the research, such as photocopying and postage.

Yours faithfully,



Dr. Mark Finn

Chair of the School of Psychology Ethics Sub-Committee

Stratford Campus, Water Lane, Stratford, London E15 4LZ  
tel: +44 (0)20 8223 4966 fax: +44 (0)20 8223 4937  
e-mail: [mno.davies@uel.ac.uk](mailto:mno.davies@uel.ac.uk) web: [www.uel.ac.uk/psychology](http://www.uel.ac.uk/psychology)



The University of East London has campuses at London Docklands and Stratford  
If you have any special access or communication requirements for your visit, please let us know. MINICOM 020 8223 2853



## ***Appendix 4: Participant invitation letter***

### **UNIVERSITY OF EAST LONDON**

School of Psychology  
Stratford Campus  
Water Lane  
London E15 4LZ

#### **The Principal Investigator**

Emily Tait

[U0814928@uel.ac.uk](mailto:U0814928@uel.ac.uk)

tel: 07708 326986

#### **Consent to Participate in a Research Study**

The purpose of this letter is to provide you with the information that you need to consider in deciding whether to participate in a research study. The study is being conducted as part of my Professional Doctorate in Counselling Psychology at the University of East London.

#### **Project Title**

An investigation into the lived experience of HIV-positive African women living in the UK.

#### **Project Description**

I want to have a better understanding of what it is like for an African woman living in the UK to be diagnosed and live with HIV. I hope that this understanding will be of benefit specifically to African communities living in the UK, but also provide a better understanding of living with HIV cross-culturally. One of the aims of the research is to provide guidelines for health workers (professional and lay workers) in assisting and supporting HIV positive individuals, based on their primary psychosocial needs and concerns.

#### **What will happen to me if I take part?**

- You and the manager of the HIV organisation or your support worker will arrange a time and place for the interview that is convenient for all involved.
- The questions you will be asked will relate to your experience of living with HIV. The questions will be given to you prior to the interview.
- The interview will be recorded on a mini voice-recorder and will last approximately one hour.

- If you decide to take part, you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect you in any way. Your decision will have no impact on the support, care or treatment that you may require in the HIV centre/charity. If you do agree to be interviewed but find any questions too distressing, you do not have to answer them.

### **What will happen to the results of the research study?**

Once the study is completed, I will be compiling a report on my findings, but you will never be identified as an individual – all people who take part in the study will be represented by an anonymous number or an agreed pseudonym. You will be asked whether you would consent to a subsequent interview once the analysis has taken place to offer your feedback on the thematic analysis and ensure that the participants' statements were appropriately represented by my interpretations.

### **Are there any risks involved in taking part?**

It is expected that the risks involved in taking part in this study will be low, however you may find that recalling and talking about your experience is distressing. If you do find any of the questions upsetting and would like to talk about this, please feel free to talk this through with me (contact details above) or your doctor/nurse or care giver who you are in contact with at the HIV centre/charity organisation. If you agree to be interviewed, I will also provide you with details of where you can obtain further support.

### **Confidentiality of the Data**

Any information you provide will be treated in strict confidence and will have your name, address or any other personal information removed so that you cannot be recognised from it. All anonymised information from the interview (transcribed) will be kept either in a locked filing cabinet or on a password-protected computer in line with the Data Protection Act. Only my supervisor and I will have access to this. When the study has been completed, you will be offered the opportunity to have the transcript of the interview returned to you, otherwise all interview recordings will be erased but anonymised transcripts may be kept for further analysis. After completion of the study or possible publication, all data will be destroyed.

### **Location**

You and the manager of the support centre or your support worker will arrange a time and place for the interview that is convenient for all involved.

### **Remuneration**

As a small token of my appreciation, when the interview is finished, I will give you a £15 voucher for your travel expenses and time.

### **Disclaimer**

You are not obliged to take part in this study and should not feel coerced. You are free to withdraw at any time. Should you choose to withdraw from the study you may do so without disadvantage to yourself and without any obligation to give a reason.

Please feel free to ask me any questions. If you are happy to continue you will be asked to sign a consent form prior to your participation. Please retain this invitation letter for reference.

If you have any questions or concerns about how the study has been conducted, please contact the study's supervisor [Dr Kendra Gilbert, School of Psychology, University of East London, Water Lane, London E15 4LZ.  
(Email : kgilbert@uel.ac.uk)

**or**

Chair of the School of Psychology Research Ethics Sub-committee: Dr. Mark Finn, School of Psychology, University of East London, Water Lane, London E15 4LZ.  
(Tel: 020 8223 4493. Email: m.finn@uel.ac.uk)

Thank you in anticipation.

Yours sincerely,

Emily Tait

12/07/12

## ***Appendix 5: Participant information sheet***

### **Information sheet for participants**

#### **An investigation into the lived experience of HIV-positive African women living in the UK.**

You are being invited to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask me if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

#### **Why have I been chosen?**

You have either responded to a participant recruitment notice seen in your HIV support centre or you have been informed about this study by a support worker at your local HIV support centre/charity and he/she has suggested that you might be prepared to talk about your experience of living with HIV as an African woman living in the UK.

#### **What is the purpose of the study?**

I want to have a better understanding of what it is like for an African woman living in the UK to be diagnosed and live with HIV. I hope that this understanding will be of benefit specifically to African communities living in the UK, but also provide a better understanding of living with HIV cross-culturally. One of the aims of the research is to provide guidelines for health workers (professional and lay workers) in assisting and supporting HIV positive individuals, based on their primary psychosocial needs and concerns.

#### **Do I have to take part?**

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and will be asked to sign a Consent Form. If you decide to take part, you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect you in any way. Your decision will have no impact on the support, care or treatment that you may require in the HIV centre/charity. If you do agree to be interviewed but find any questions too distressing, you do not have to answer them.

#### **What will happen to me if I take part?**

- You and the manager of the HIV organisation or your support worker will arrange a time and place for the interview that is convenient for all involved.
- The questions you will be asked will relate to your experience of living with HIV. The questions will be given to you prior to the interview.

- The interview will be recorded on a mini voice-recorder and will last approximately one hour.
- As a small token of my appreciation, I will give you a £15 voucher for your travel expenses and time.

### **Will my taking part in this study be kept confidential?**

Any information you provide will be treated in strict confidence and will have your name, address or any other personal information removed so that you cannot be recognised from it. All information from the interview will be kept either in a locked filing cabinet or on a password-protected computer in line with the Data Protection Act. Only my supervisor and I will have access to this. When the study has been completed, you will be offered the opportunity to have the transcript of the interview returned to you, otherwise all data will be destroyed.

### **What will happen to the results of the research study?**

Once the study is completed, I will be compiling a report on my findings, but you will never be identified as an individual – all people who take part in the study will be represented by an anonymous number or an agreed pseudonym. You will be asked whether you would consent to a subsequent interview once the analysis has taken place to offer your feedback on the thematic analysis and ensure that the participants' statements were appropriately represented by my interpretations.

### **Are there any risks involved in taking part?**

It is expected that the risks involved in taking part in this study will be low, however you may find that recalling and talking about your experience is distressing. If you do find any of the questions upsetting and would like to talk about this, please feel free to talk this through with me (contact details below) or your doctor/nurse or care giver who you are in contact with at the HIV centre/charity organisation. If you agree to be interviewed, I will also provide you with details of where you can obtain further support.

### **Contact for further information:**

You are always welcome to contact me for more information, or if you have any concerns.

Emily Tait  
u0814928@uel.ac.uk

tel: 07708 326986

Thank you for kindly considering taking part in this study.

(Please keep a copy of this information sheet and a copy of the signed Consent Form.)



**PARTICIPANT RECRUITMENT FOR  
COUNSELLING PSYCHOLOGY DOCTORATE RESEARCH**

**What is your experience of living  
with HIV?**

**What has helped you to live with  
your HIV-positive status?**

- **Suitable participants will have been diagnosed as HIV-positive for more than 1 year and have been born and raised to African parents in Africa until at least age 12 and have a fluency in spoken English**
- **This study will explore what it is like for a black African woman living in the UK to live with HIV**

Your participation would involve a single, face-to-face 60-minute interview with me, which would take place at a convenient time and place for you. The interview will be audio recorded, with any material that may potentially aid identification removed.

Thank you for taking an interest in this research. If you decide to take part, your participation would be greatly appreciated and I will give you a £15 voucher for your travel expenses and time.

For more information about this study, or to volunteer, please contact:

**Emily Tait**    *Counselling Psychology trainee*  
Email:        **u0814928@uel.ac.uk**

*This study has been reviewed by, and has received ethics clearance through, the University of East London Ethics Committee*



## ***Appendix 7: Informed consent form***

### **Consent form for Participants**

Title of project: An investigation into the lived experience of HIV positive African women living in the UK.

Researcher: Emily Tait

I have read the information sheet relating to the above study and have been offered the opportunity to ask any questions.

I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason.

I understand that if I refuse to take part, this will not have any impact on my support, care or treatment.

I agree to the interview being tape-recorded.

I understand that all data from the research will remain strictly confidential. Only the researchers involved will have access to the data. It has been explained to me what will happen to the data after the research study has ended.

Name of  
participant.....

Signed.....

Date.....

Name of researcher:        Emily Tait

Signed.....

Date.....

## ***Appendix 8: The sample and participant demographics***

### **Participant characteristics and demographics**

| <b>Participant pseudonym</b> | <b>Age</b> | <b>Approximate length of time diagnosed</b> | <b>Marital Status</b> | <b>Country of birth</b> | <b>Time in the UK</b> | <b>Number of children</b> |
|------------------------------|------------|---|-----------------------|-------------------------|-----------------------|---------------------------|
| Melitta                      | 38         | 10 Years                                    | Single                | South Africa            | 6 Years               | 0                         |
| Lukiya                       | 47         | 15 Years                                    | Single                | Uganda                  | 17 Years              | 1                         |
| Annette                      | 40         | 12 Years                                    | Married               | South Africa            | 10 Years              | 2                         |
| Sarah                        | 65         | 10 Years                                    | Widowed               | Uganda                  | 11 Years              | 3                         |
| Soffia                       | 50         | 22 Years                                    | Single                | Uganda                  | 16 Years              | 2                         |

## **Appendix 9: Smith's (2011, p.24) guidelines for quality in IPA research**

**The paper should have a clear focus.** Papers providing detail of a particular aspect rather than a broad reconnaissance are more likely to be of high quality. This focus may be determined at the outset or emerge during analysis. This focus is apparent in many of the good IPA papers illustrated, for example, Chapman et al. (2007) examine the impact of one particular technology in heart disease. Turner et al. (2002) sample one specific group of ex-professional sports players.

**The paper will have strong data.** Most IPA is derived from interviews and this means that, for the most part, getting good data requires doing good interviewing. This is a particular skill that must not be underestimated. The quality of the interview data obtained sets a cap on how good a paper can subsequently be. Examples of good data are given in many of the summaries of good papers presented earlier. High-quality data is integral to the success of these papers.

**The paper should be rigorous.** One should aim to give some measure of prevalence for a theme and the corpus should be well represented in the analysis. Extracts should be selected to give some indication of convergence and divergence, representativeness and variability. This way the reader gets to see the breadth and depth of the theme. For papers with small sample sizes (1–3), each theme should be supported with extracts from each participant. For papers with sample sizes of 4–8, in general, extracts from half the participants should be provided as evidence. For larger sample sizes, researchers should give illustrations from at least three or four participants per theme and also provide some indication of how prevalence of a theme is determined. The two papers on chronic fatigue syndrome by Dickson et al. (2007, 2008) have, for IPA, a relatively large sample size. Their persuasiveness is enhanced by careful articulation of measures of prevalence. The overall corpus should also be proportionately sampled. In other words, the evidence base, when assessed in the round, should not be drawn from just a small proportion of participants.

**Sufficient space must be given to the elaboration of each theme.** In certain circumstances it may well be better to present a subset of the emergent themes so there is room to do justice to each, rather than presenting all themes but doing so superficially. The French et al. (2005) paper on patient explanations for heart attack is enhanced by having an extended and elaborate account of one of the emergent themes.

**The analysis should be interpretative not just descriptive.** An interpretative commentary should follow each of the extracts presented. The author is thereby showing the particular ways extracts are contributing to the unfurling theme. In order to do this the researcher is engaging in the double hermeneutic: trying to make sense of the participant and trying to making sense of their experience. For further discussion on pushing interpretation deeper, see Smith (2004).

**The analysis should be pointing to both convergence and divergence.** Where an IPA study reports data from more than one participant, there should be a skilful demonstration of both patterns of similarity among participants as well as the uniqueness of the individual experience. The unfolding narrative for a theme thus provides a careful interpretative analysis of how participants manifest the same theme in particular and different ways. This nuanced capturing of similarity and difference, convergence and divergence is the hallmark of good IPA work.

**The paper needs to be carefully written.** Good qualitative work always requires good writing. The reader will feel engaged by a well-wrought, sustained narrative. As a result, he/she will consider they have learned in detail about the participants' experience of the phenomenon under investigation. Have a look at some of the papers rated good in this review to see what good writing looks like.

## ***Appendix 10: Interview schedule***

### **Interview Schedule**

- 1) How would you describe yourself? Prompt: Most important characteristics? What do you like or not like about yourself?
- 2) What is it like to have this identity? Prompt: What is it like to be you? What is it like to experience yourself in the way you've just described?
- 3) Where do you think your ideas about yourself come from? Prompt: Particular events (memories or stories)? Comments? Influenced of others? Family? Peers? Media? Positive and negative influences?
- 4) How would you describe yourself before your HIV diagnosis? Prompt: What was it like to be you before you learned you were HIV positive?
- 5) Has the way you view yourself changed since the time before your HIV diagnosis? Prompt: In what way? Positive/negative? In what way? Experiences support this?
- 6) How would you describe your ethnic identity?
- 7) What does it mean to you to be black African (or specific nationality if given)? Prompt: How much does being black African play a part in your identity? How has being HIV positive played a part in your ethnic identity?
- 8) What is your experience of being black African living in the UK? Prompt: How does the experience of your ethnic identity differ from your home country?
- 9) How would you describe what life is like living with HIV? Prompt: Any particular experiences that come to mind?
- 10) What is it like to be HIV positive living in the UK? Prompt: How does it compare with your experiences living in your home country?
- 8) How have you learned to live with the illness? Prompt: On a day-to-day basis, how do you deal with being HIV positive? Strategies? Personal strengths? Practical or emotional or mental forms of coping? Beliefs you hold about life?
- 9) What do you think your future will look like? Prompt: Do you think the way you view yourself changes and may change in the future? In what way?
- 13) Is there anything else that is important for me to know about to understand your experience
- 14) How has it been for you talking with me today? Prompt: Any questions or concerns?

### ***Appendix 11: Key for the presented extracts in the results section***

In presenting the verbatim extracts some minor changes have been made to improve readability. Minor hesitations, word repetitions and utterances such as “erm” and “you know” have mostly been removed. Missing material is indicated by dotted lines within brackets (...), and where material has been added (e.g. to explain what a participant is referring to) it is presented within square brackets. Dotted lines at the beginning or end of an extract indicate that the person was talking prior to or after the extract. All identifying information has been removed or changed, and the alias names used in the Method chapter have been maintained to protect the anonymity of participants.

## ***Appendix 12: Illustrative quotes for master themes and subthemes***

### **Quotes for Super-ordinate Theme One: Given Life but it's a struggle**

"...there's a constant internal battle that goes on with myself" (Melitta)

| <b>Quote</b>   | <b>Interview and line number</b> |
|--|----------------------------------|
| I'm constantly having to remind myself that I can't change the HIV status and I also can't be in control of it so there's a constant internal battle that goes on...um with myself. I can't put the HIV status out of my mind although I've been fine on the medication but I can't put it out of my mind, it's always there and it's a reminder of the fact that I can't control it     | Melitta lines 76-81              |
| That means sometimes I think I am joy, but sometimes I say no, I'm not joy because if you've got the drugs, yeah, you take them, but you aren't cured. It's still no good, you say "What is this? I feel okay," no, you are still sick.  | Sarah lines 276-279              |
| you have a chronic illness it's really bad because always it's sweeping back to your mind and I don't know what is going to happen (...) at the hospital they keep saying they're going to (...) "Oh really the cure is coming?" then they say (...) and of course you see still people are dying and again they're not dying all the time because of the medication                     | Lukiya lines 174-180             |
| So I had so many who had died back home, from my mum, from my uncles, we are like 40 something in the family. Yeah, and my sibling, the only surviving one, we only three and they too, you know, positive, HIV positive. And one of my brothers died here, he actually was here as well and the others...so he died, Tom. So it was really like you just lose hope, you just lose hope. | Lukiya lines 131-138             |

### Medication: Friend or Foe?

| <b>Quote</b>  | <b>Interview and line number</b>       |
|---|--|
| the medication, give me the medication but the medication for two years kept on making me worse and worse. I don't know if I was on the wrong medication or what, I don't know. Because they kept on medicating me like...for a while I had no hair, I was very thin, I couldn't eat, it was black like a charcoal, like the shoes, so it was really quite serious  | Lukiya lines 144-148                   |
| I have HIV and I'm always in pain you know this disease is so bad and I have to take medications all the time and I hate it...it takes over my life...ya everyday I'm always worried and it's always on my mind that I must take the medications and I can't forget because it's...um...I'm always painful you know...it's always there [...] I haven't got many people to understand but some of the doctors know and sometimes they are nice but...ya...I don't know...it's just very bad | Annette lines 28-36                    |
| I had no choice, I had no choice...I kept on changing the medication...you find yourself like sometimes with a lot of pains and apathy, no energy, but you are there...okay you will not have the quality of life you had but at least it will prolong, you know, it is better than nothing.  | Lukiya lines 159-160, 166-168, 176-178 |

|  |                      |
|--|----------------------|
| So it's a good thing to be here and have good life and be looked after. Maybe if I was back in Africa I would have been passed away a long time ago, but now I'm going, I'm okay. And what do you think your future will look like? (Researcher) My future is brightening a lot.   | Sarah lines 795-800  |
| It is not in my mind but for me except when I get a different sick...but now the medication it isn't in my mind, it is like in my food, I don't care. I know how I take it.  | Soffia lines 487-493 |
| On a day-to-day basis taking medication all the time, that is frustrating and in the morning, like yesterday I forgot to take my medication, I told you, I think I've got vitamins, but I've got to take them three at nine, they say "Why don't you put them in your bag?" I say "I'm tired of coping with them in my bag," so now that I make sure the rest I have taken them, so I take one and they go back. I sometimes forget. | Sarah lines 689-695  |
| (Do you think that's different though now that you're on medication?: Researcher)<br><br>Yeah, of course. By the time I was with HIV it was 1997, that's when the drugs came in so I went straight away but you know if it wasn't there I know I would have died...  | Lukiya lines 117-121 |

"Life is like a prison" (Annette)

| Quote   | Interview and line number  |
|---|----------------------------|
| life is like a prison...I have to stay at home in my bed and I get so depressed and I don't even open my curtains...<br>...I don't want to see anyone (...) I just don't want to leave the house because if I leave the house I'm always thinking I want to be back there because it's safe and I can be on my own because no one understands, well the people in the support group do but it's not every day so when I'm not there I stay at home (...) when I'm sleeping I can escape because for some time I'm forgetting... | Annette lines 45-47, 51-58 |
| ...you are trapped in something...<br>...because you are like in there (referring to her HIV-positive status) where you can't move out, you can't explore...  | Lukiya lines 340, 351-356  |
| Bad, very bad [...] I am so alone and my son must come home from school sometimes to help me and to check on me and my girl...she doesn't know I'm HIV.   | Annette lines 62-64        |

Letting go of who I was

| Quote   | Interview and line number    |
|---|------------------------------|
| It impacted on me, I lost so much because when I studied in Moscow I will be finishing, I would be somebody, I will be having a good family, a good husband and my life will be, my holiday with my children and I would be having a good job, because I did finance (...) nobody is going to give you jobs when you go away all the time, you have appointments (...) you can't wake up, you are not yourself (...) sometimes you can't sleep... | Lukiya lines 99-103, 332-336 |
| I've been HIV for so long I have to appreciate what God giving me now, not to start to look for others which I can't afford, I can't even look at   | Soffia lines 589-594         |

|  |                       |
|--|-----------------------|
| something which I can't afford (...) for me, once I know something that I can't afford it I can't put it in my mind...   |                       |
| ...you are always living like on borrowed time.  | Lukiya line116        |
| I can't control my life like I used to and I had so many plans and dreams and now it's all gone but at the same time I have life (...) many things have changed, now I think life is very short and I'm so thankful for being alive...   | Annette lines 180-185 |
| ...you don't have so much hope for tomorrow so you just want to live the day as it comes.  | Lukiya lines 109-111  |
| I have to be in a circle with people who are HIV normally, yeah. You can't really socialise so much out there with the others, you can't be like with your fellow students, former students  | Lukiya lines 194-197  |
| ...my life before was more full and now it's empty, well um, it's now got different things in it, it's filled with different things  | Annette lines 108-110 |
| ...you know, you are not somebody who is going to be liked. You are sick, off sick a bit too much, if not off sick you ache, your appointments.  | Lukiya lines 343-345  |
| What I don't like about myself is of course not feeling well, yeah, and like not having proper energy, yeah, energy. You feel aches all the time, no energy, so yeah.  | Lukiya lines 322-324  |
| ...because now all my life prime time has gone, wasted, like I said, because of the illness and the hours even if a few comes I don't want to be doing much as you done before, so you always look, you see whatever comes. You live day by day, yeah, what you will be coming tomorrow and next week and that.                      | Lukiya lines 778-782  |
| ...but it's not like the quality of life you would have, you know, like somebody who studied really you'd have wanted to just go and make around and having that thing on you, you know. In your head you are supposed to be somewhere nicer, you know, having life full of...or be full of life and a good life with your children. | Lukiya lines 206-211  |
| ...you don't like yourself anymore. You are just like "Oh, all my life is spoiled now, all whatever I was," all my like hopes and whatever they are all...so I am like you're not like a person anymore, yeah.   | Lukiya lines 655-658  |

### Quotes for Super-ordinate Theme Two: A Will to survive

That's strong minded is what it is. Africa is strong (Lukiya)

| Quote   | Interview and line number          |
|---|------------------------------------|
| I'm still alive (...) if I was not here the truth is I shouldn't be alive (...) I'm a survivor completely...  | Soffia lines 526-528               |
| ...I am black and I am African and it means I'm proud you know, it's something that I am and I haven't been something else (...) it's like what God gives me I must continue and I must live with (...) the African people are different to the British because we don't have everything we need and we don't get money and so we are survivors and so maybe I'm a survivor for that, maybe I keep going forward because otherwise we die, that is maybe the same for me with this HIV... | Annette lines 422-432              |
| you have really to try hard and you prove yourself then you know you will make it (...) I try by managing whatever comes (...) that's strong minded is what it is, Africa is strong (...) we are like that because I have a will to live (...) otherwise you find yourself you can't do much, but in  | Lukiya lines 473-474, 496, 508-518 |



|  |                               |
|--|-------------------------------|
| the mind, you have it there, you are strong in mind.   |                               |
| I'm African and even I'm treating my children like African, I don't want to change them, people over here never change me. I'm African completely. I don't want to follow their ways (...) I have a British passport but I never call myself British, I know I am African, I will never be a British citizen, never, I'm African.  | Soffia lines 819-823, 830-834 |
| ...it makes me fight harder for who I am, I want people to see my ethnic values and maybe to a degree know and or somehow understand the struggles I go through as a black African in a different country and also as somebody with HIV in a different country.  | Melitta lines 372-376         |
| It is the peer support from my African people, community, I go to groups, yeah.  | Lukiya lines 550-551          |
| I'm happy, I'm a survivor completely   | Soffia lines 505-506          |
| A survivor...I am a survivor...I am winning this fight with my HIV...for now and so I try to think well and good thoughts even though the pain and you know also we have good and bad days...always so just get through each day and then tomorrow you might...it might be a better day..and you know you will then you know you got through it (smile)                                    | Annette lines 570-575         |
| I know where I come from, I'm an African. Because like I said you know I had some struggles somewhere (...) but for me I know from the grass root where my grandparents were born, I know where they are. That's very important.<br>...It's important for me that I know where...even if I die I hope that my body will be taken back to Africa. I'm proud of my...very proud of my roots. | Sarah lines 574-578, 581-583  |

### The value of support groups

|  |                       |
|--|-----------------------|
| The doctor, the social worker, everyone where you go, whom you are talking to is nice to you, they also help me to survive. And there is support group where you are going to make you beauty your body again (...) I'm not going to die and even to take it out your mind, you see back at home you can't see those, it's so important the support group... | Soffia lines 212-218  |
| African culture is very supportive and we have our big family and live together as one and we share but the African people are different to the British...   | Annette lines 426-428 |
| I might find more people that are HIV-positive that I could form a support group with and maybe try and create that kind of social support and accepting of me that I would have normally got from my African family   | Melitta lines 443-446 |
| Keeping going, you're happy with great friends, you go out, you go like you are coming here, you go and meet somebody, we go to another place, we talk, that's a good thing because you are strong, you feel you are strong.   | Sarah lines 159-162   |
| ...we are all accepted and we don't have to worry about the judgement (...) it's the place (support group) where I can be myself and I don't have to hide, yes maybe it's the one place I am free (...) sometimes I wonder what I would do without these people, these other Africans with the same problems.  | Annette lines 253-258 |
| The support groups helps in a lot of things because (...) they bring there people, people ask questions, they advise people what to do and they  | Lukiya lines 619-631  |

|   |                     |
|---|---------------------|
| get other groups. They advise not only medical, housing, lawyers, people with new questions that ask. So you feel there is, you know, a home somewhere whereby they always have a solution for something, yeah, so which has really done a lot of impact and I think that's why some people hope we're not like damned. There are some are there, those who have so much strength they are going back   |                     |
| Because when you grow older have someone I can be with. At least kids are grown up, they are grown. One thing is that my, I had those children and a husband, I had still, but for him it's okay, he has all the money, so he will be okay but for me, I am alone, yeah.<br><br>(And what does that mean for you?: Researcher)<br>You feel lonely, so a bit lonely, loneliness.   | Sarah lines 313-319 |
| (And what you get from the support groups?: Researcher)<br>Socialise, that's a bit of socialising.<br><br>(And what does socialising mean for you?: researcher)<br><br>In touch with other, talk with people, exchange ideas. Talk about medication, how does your medication do, how do you feel? You can tell some symptoms, maybe some of the symptoms are the same as yours. How do you go about it? Some they say you can do this, you can do this, you can walk, you can exercise, try to change your diet to help you. | Sarah lines 382-390 |

#### Defending against social stigma

| Quote   | Interview and line number     |
|---|-------------------------------|
| To keep going, you said you were strong, what helped you?" (Researcher)"...the thing which is making me to be strong (...) I didn't get it from nowhere, I get it from my husband (...) you don't want even people to see you when you start to get sick who don't know where you get it but for me everyone was aware about it (...) it was making very different because most of the people I didn't hide, it doesn't need to hide (...) I was very different (...) I was strong and to be strong it makes you to survivor... | Soffia lines 117-133, 692-696 |
| I suppose less people with it and it's less frowned upon in Africa because I think somehow here they think it's a gay disease or it's a sort of (pfft) female sort of slept around whereas in Africa (pfft) usually women are getting from their husbands, it's that sort of thing.   | Melitta lines 209-213         |
| They think you are a crook, sleeping so many different men getting HIV, whereas you can be with one person with HIV and get it, so many people they don't know (...) I know I'm not dirty and I wasn't bad and I didn't go sleeping with other men so I'm not feeling bad about that and the people who think badly about me, well what can I do?   | Sarah lines 133-135, 147-150  |
| ...I feel frustrated and ashamed when I hear people talking about HIV but not in the support group, it's only really with people who don't know and will think you are bad and dirty...   | Annette lines 222-225         |
| ...it was like something which you fear, you fear yourself and say, "My God, I don't think I can be near somebody like that"<br>Do you still feel like that sometimes? (Researcher)<br>No I don't because now I have all the understanding, the knowledge,  | Lukiya lines 282-287          |

|   |                      |
|---|----------------------|
| how you can get HIV, I know that but before I wasn't.   |                      |
| ...they are ignorant about HIV  | Lukiya line 269      |
| ...they think you are contagious and they must stay away  | Annette line 229     |
| I was very strong even at the beginning because I didn't fear anyone because everyone was aware about it. | Soffia lines 680-682 |

### Quotes for Super-ordinate Theme Three: Positive coping

#### Doing vs being

| Quote   | Interview and line number             |
|---|---------------------------------------|
| ...to be keeping busy because sometimes you can think too much and that's not good (...) it can't go away from my brain but sometimes if I'm busy it's helping me (...) appointments and support groups and the doctor and to take medication and be a good mum and be thinking about what you can control, that makes it easier (...)I can't do many things anymore, no job, no partner, no freedom, always pills and not to keep busy is bad (...) sometimes I find my life bad like I would in prison, my life before was more full and now it's empty, well (...) it's filled with different things   | Annette lines 515-528                 |
| (“...do you think that's changed the way you think about yourself?: Researcher)<br>“ Yeah (...) I've changed myself my way of thinking.”<br>(“How has your way of thinking changed?: Researcher)<br>“Way of dressing up, eating, eating.”<br>(“On a day-to-day basis how do you feel emotionally?: Researcher)<br>“On a day-to-day basis (...) I do my shopping, I bake things, I do my washing, my ironing, I do my cleaning the house, I do my cooking...”<br>“I'm happy I wake up, I do my work, I go on the bus, I go to the city, the shopping, that's it, I feel happy, just look at me, still happy.”<br>(“Oh that's good. What other things make you happy?: Researcher)<br>“Socialise” | Sarah lines 515-520, 188-191, 338-345 |
| I can't stay in the house (...) my brother said, 'you go out as if you're working, you go in the morning, you come back at night', that's how I am.”<br>(“Why do you think you do that?: Researcher)<br>So that I be strong.  | Sarah lines 705-709                   |
| So I try and control the parts of my life that I can because that one major one I can't...  | Melitta lines 472-473                 |
| I would like to be more busy sometimes I find my life a bit boring like I would in prison   | Annette lines 107-108                 |
| (What is happiness?: Researcher)<br>It's money, money that makes someone happy and relationship, to be lonely also it is not good, be lonely you need to be with someone  | Soffia lines 414-417                  |
| Any mental forms of coping?: Researcher)<br>Coping? I try sometimes to forget that I'm now like this, Going out, going shopping, with the shopping that's the most thing I do.  | Sarah lines 770-772                   |
| Being black and living in the UK I'm okay because I get whatever I want, my African food I get from here (...) fresh food from Kampala, fresh banana, sweet potato, everything.   | Sarah lines 626-630                   |
| ...maybe you know I just I just must learn to move on, maybe that's what I've done, moving forward it's better (laugh)  | Annette lines 378-380                 |

“My body is shining, you can’t even know I’m positive” (Soffia)

| Quote  | Interview and line number     |
|--|-------------------------------|
| <p>“...in Africa someone even who has money, they wouldn’t have my body (...) you can’t even see anything at all my body is shining, you can’t even know I’m positive.”</p> <p>“...and you don’t want to look with HIV, you want to look nice in front of people...”</p>   | Soffia lines 245-252, 189-190 |
| <p>“I sometimes feel like I’m getting somewhere and making progress with this HIV but then I go on the bus and I wonder what they are thinking and if they can know I am HIV-positive but I know they can’t but I feel like (...) sometimes it’s like people can see me, the real me even though I don’t like to disclose my HIV status to everybody...”</p>   | Annette lines 124-130         |
| <p>Now I started to look nice even before getting paper, I accept it, I can’t solve it</p>   | Soffia lines 623-624          |
| <p>(How would you describe yourself before your HIV diagnosis?: Researcher)</p> <p>Before I was very smart.</p> <p>(You were smart?: Researcher)</p> <p>Yeah, putting on very well. I’m sure I have been at my best some years before.</p> <p>(Really? Oh that’s wonderful: Researcher)</p> <p>Because I was size 8, maybe size 10 but look at me now.</p>   | Sarah lines 467-474           |
| <p>(What about your psychological, what about your way of thinking, how has that changed?: Researcher)</p> <p>When I went to Uganda, I want to explain this, when I went to Uganda people were admiring me, “Wow, you look nice,” I said “What?” “Wow, look at your skin,” I said “What?” So people were seeing something different for me. I say “Oh, so I’m like this?” Whatever I was dressing up they say “Oh, where did you buy this one? (...) admiring me which is good...”</p> | Sarah lines 521-530           |
| <p>(And why do you think it’s important to be admired? You said to be admired it was good: Researcher)</p> <p>Because I felt power you see, they see some good from me it fills everyone you see, they didn’t see anything, they say “Oh that looks good, look at you, you are even younger, look at you,” I said “How?” and I was so proud, and in the sunshine I was really sparkling.</p>   | Sarah lines 550-556           |
| <p>I’m a survivor, I’m always calling myself survivor, I’m happy. I took my, I just wanted to look after myself, I took out the word HIV, I know I am HIV, I just want to look nice to so...to make someone who is come talk that one is...to keep quiet, because when you look nice you can’t even talk to someone who is look nice more than you, you just keep quiet.</p>   | Soffia lines 268-274          |

## Quotes for Super-ordinate Theme Four: Negotiating a stigmatised identity

### Keeping the identity secret

| Quote   | Interview and line number                        |
|---|--|
| It is very, very important (appearance) and once you get skin disease (...) you know that you're HIV you can think that everyone look at you knows that you are, no one want everybody to know (...) you can't hide yourself with this thing which is bad   | Soffia lines 276-281, 290-291                    |
| <p>...I'm actually not really living truthfully and that concerns me, I've got friends who actually don't know me because I haven't told them that I'm HIV positive and at the same time I don't know why that should define me but it does..."</p> <p>"...it's a culture that has honour and integrity and strength and honesty and those are valuable attributes that I've got from just being who I am and they are very important to me and that's why I do struggle a bit with the fact that I sort of live a lie here by not telling people"</p> <p>"...I'm more guarded because I'm often nervous that I'm going to let it slip that I'm HIV-positive in the fear of being judged..."</p> <p>"...socially I don't allow people too close because I don't want to disclose (...) so it's easier just to have slightly more superficial friendships.</p> | Melitta lines 264-268, 308-312, 480-482, 514-517 |
| ...disclosure, it depends, you are disclosing for who and for what (...) you have to think how they are going to take it and again you think of the impact...   | Lukiya lines 259-262                             |
| ...whenever I tell someone they will go, that certainly was in my mind. So I'm still needing the men, anyway how am I going to get them? If I'm keeping on telling them they will tell other people that that one is like that, that it was in my mind every time...  | Soffia lines 356-360                             |
| She said "Oh mum, what my worry is when my friends will find out you are like that" and so at first she cannot tell all this, they tell them to keep it secret which they all do but she said [inaudible 0:20:20] "Now if I'm going to get married, then I have to disclose to my husband, because what if he finds out and says I can't come to that family (...) you always hear like people, children in the schools, when they find out, their parents, whatever, they start discriminating there.  | Lukiya lines 242-251                             |
| I think there I, I personally think that I'd have less understanding here than there...um I think it would be more difficult for people to accept the whole HIV thing because it's so much more in the minority here than what it is in Africa.   | Melitta lines 198-201                            |
| I also don't know why HIV should define who I am and I do fear that there would be rejection from people if they did know...ya...and that would once again be a control issue...maybe that's what I'm trying to do is control my friendships or keep them I don't know.   | Melitta 272-276                                  |
| I was happy to disclose back home because there was more understanding and I certainly encourage everybody else to disclose and I always have this thing about honesty and living an honest life and being truthful with yourself and now I'm not doing that so I just...ya...um...so only half of me is actually known so do I have true friends I don't know...maybe not.   | Melitta 396- 402                                 |
| <p>(So how is the stigma different there to here?: Researcher)</p> <p>Different between here and there because that one is your home country. They know you from grass root. No, I won't go but here who</p>  | Sarah lines 437-442                              |

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| knows you? Yeah. But in Uganda you go to this one, you do that one and that one, they will see you go past, "Oh they are dead," and you go that one, see the families, there, but here, no. |  |
|---|--|

"We are black and we have HIV so we have both hard things" (Annette)

| Quote   | Interview and line number      |
|---|--------------------------------|
| ...we are black and we have HIV so we have both things, both hard things (...) the stigma here about black people is terrible, not only the HIV (...) African is beautiful and African is strong but in the world it's discriminated like so is HIV so maybe both of those things makes a difference to how I am...                     | Annette lines 392-395, 437-440 |
| ...it's quite lonely, I suppose being black African in the UK is as lonely to a degree as being HIV-positive in the UK and doubly so if you put the two together (...) I'm almost a statistic (...) if I disclose the opinion's going to be "she's black, she's African, obviously got AIDS" so I sort of don't want that stereotype... | Melitta lines 354-356, 413-416 |
| ...you lose hope because again, HIV, the diagnosis which puts you down and again you are black, again it slaps you again on the other side.   | Lukiya lines 410-412           |
| ...but being black of course you have to manage by yourself, so you have to really to be, to excel, that word, excel?<br>(Excel, yeah. Do you think so?: Researcher)<br>Yeah, yeah, you have to excel so much.<br>(So you have to excel more than somebody else maybe?: Researcher)<br>Yeah, more than the white people, yeah.          | Lukiya lines 437-442           |
| ...and I think when they look at you, you sort of think well you're black and you come from Africa and you've probably got AIDS.  | Melitta lines 186-188          |
| ...on the one hand being black African you can disclose and on the other hand having HIV you feel you can't disclose.   | Melitta lines 383-385          |
| ...when you are black and from Africa...shew...I don't know but the people here they judge you.   | Annette lines 333-335          |
| there are actually a lot of black African people in London so that is better. I remember I thought when I first came oh my God what will these English people think about me...but when I came...when I came here there were already so many many African people...for me that was better.  | Annette lines 401-406          |

**Quotes for Super-ordinate Theme Five: Recognising a new me**

| Quote  | Interview and line number               |
|--|---|
| Of course the diagnosis of HIV-positive, whatever I am today it's that diagnosis.<br>(“Anything else?: Researcher) No  | Lukiya lines 402-404                    |
| I think it's lifted the lid of a lot of things I knew about myself but was maybe not sure that I could express it whereas that (...) gave me the courage maybe to live up to who I actually knew I was (...) I knew that I had those traits (...) a go-getter (...) like to see the positive, I knew | Melitta lines 109-112, 123-130, 139-146 |

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| those things but I lived them without much thought and then when the HIV came (...) I felt like I'd lost control so I had to work really hard to get that part of me back again (...) I now realise (...) the HIV has been a huge blessing to me emotionally because I've learned so many things about myself whereas if I hadn't I would have lived in (...) oblivion to my potential (...) I would have just lived on the surface, the HIV's made me have to evaluate who I am and what I want to do with myself and my life.              |                       |
| ...in a way I'm different to how I was before because I didn't have this HIV part of me (...) it's like one day you have no child and then nine months later you are a mum and everything has changed, you are now a mum, life is different and you become something new   | Annette lines 147-162 |
| Yeah, of course I've changed now. Like it's short but I treasure life so much, like, you know, but life is really...you have...you have to do some good each day, you know, you are around, yeah, and if possible to try and be...use whatever you can. I mean use it, you tries it properly.  | Lukiya lines 383-387  |
| you know it's not easy to forget about it [...] it's part of my life now...no it is my life and it is me now...ya.   | Annette lines 92-94   |
| I suppose I'm stronger and wiser and I don't take things for granted as much. Every day is precious now and that's a good thing.   | Annette lines 263-265 |
| my way of fighting back is to move forward...um I'm not prepared to let...let it destroy my life or change who I am or...I feel I've given up enough anyway...enough control over my life so...  | Melitta lines 540-543 |
| So I had to accept that's who I am and I have HIV and I'm actually living quite well.  | Melitta lines 588-589 |
| I think initially I fought against being (sigh) the HIV actually um, having such an impact on my life that I became, that the HIV was who I was I fought that but now that the difference in the way I live I think is better, er emotionally I live with more intent, I live with more consciousness, I live with more um I really live everyday because I know what it's like to feel that desperate that it was I really did when I was diagnosed I thought my life was over, um and now I realise it's not actually over it's different. | Melitta lines 594-602 |
| (Do you have any particular strategies or personal strengths that help you?: Researcher) Live for who I am.  | Sarah lines 742-744   |
| In fact being HIV taught me a lot...   | Sarah line 785        |
| ...once I realised that I had a little bit of control which is what the medication did, then I settled a bit and I had more time to observe the changes and to make the best of them rather than just spiralling out of control which was what I was initially...when I was first diagnosed.   | Melitta lines 154-158 |
| Life is good, life is good, life is short and good, it's so sweet and good but short, it is very nice...   | Sarah 779-780         |

### Appendix 13: Annette's Interview Transcript

| Exploratory Comments   | Original Interview Transcript  | Emerging Themes   |
|--|--|---|
| Immediately relating to sickness but also motherhood   | (Answering demographic questions)<br><br>1) RESEARCHER: Annette how would you describe yourself?<br><br>2) ANNETTE: Ummm I um I think I'm a sick person but a good person and um I'm not sure I think um I well I'm a mother and I...I don't know actually it's quite difficult.   | Being a mum gives strength                              |
| Difficulties challenge her strength and kindness   | 3) RESEARCHER: What sort of person are you?<br><br>4) ANNETTE: Oh um I'm kind and I'm strong but things you know my life is quite difficult and I can't always be you know um with strength and I'm always in pain so yes it is difficult to be me um you know.  | Letting go of past ideas of the self that no longer fit |
| Not easy to think of what she likes about herself  | 5) RESEARCHER: What do you like about yourself?<br><br>6) ANNETTE: Oh (laugh) I don't know [...] I think...I (laugh) I don't know.   |   |
| My attempt to help her feel relaxed and relay that the question is difficult                     | 7) RESEARCHER: (laugh) It is a difficult question sometimes you know for you to answer yourself, I know.<br><br>8) ANNETTE: Ya (smile)   |   |
| Suffering with the pain from side effect of meds which seems to take over, feels quite isolating | 9) RESEARCHER: Can you think of anything you don't like about yourself?<br><br>10) ANNETTE: Oh (laugh) yes I think so (laugh)...um I have HIV and I'm always in pain you know this disease is so bad and I have to take medications all the time and I hate it...it takes over my life...ya everyday I'm always worried and it's always on my mind that I must take the medications and I can't forget because it's...um...I'm always painful you know...it's always there [...] I haven't got many people to understand but some of the doctors know and sometimes they are nice but...ya...I don't know...it's just very bad...all the time...ya | Meds provide life with challenges                       |
| Seems very   | 11) RESEARCHER: Can you tell me a bit more about what it's like to live like that?<br><br>12) ANNETTE: Ya it's bad...very very bad [...] I'm not always happy but sometimes I am but when I'm  |   |



|  |  |   |
|--|--|---|
| <p>negative and overwhelmed with the physical effects of her meds</p> <p>Physical effects make her feel depressed and hide herself</p> <p>Wants to hide, afraid of being outside the safety of her house. Feels isolated but would prefer to be with support group. Only escape in sleep. Like prison.</p> <p>Alone and keeping a secret from daughter. Role reversal of mother and son...possible shame.</p> <p>Lonely, isolated trapped</p> <p>On her own and feels alone in her own body, trapped in her body? Trapped in her own thoughts which she can't share. Compares it</p> | <p>happy I get a reminder I'm not because I'm actually in pain, the medication is making a lot of problems, it's good sometimes because I'm here but you know my legs get very sore like now, shew I can sometimes I can't walk properly and my life is like a prison, I have to stay at home in my bed and I get so depressed sometimes...a lot...and I don't even open my curtains..you know.</p> <p>13) RESEARCHER: Why not?</p> <p>14) ANNETTE: Ah you know I just don't even want to see anyone and I can't move...I eish you know it's hard...I just don't want to leave the house because if I leave the house I'm always thinking I want to be back there because it's safe and I can be on my own because no one understands, well the people in the support group do but it's not always, it's not everyday so when I'm not there I stay at home...when I'm sleeping I can escape because for some time I'm forgetting</p> <p>15) RESEARCHER: And um how does that make you feel?</p> <p>16) ANNETTE: Bad, very bad [...] I am so alone and my son must come home from school sometimes to help me and to check on me and my girl...she doesn't know I'm HIV.</p> <p>17) RESEARCHER: She doesn't know?</p> <p>18) ANNETTE: No.</p> <p>19) RESEARCHER: How old are your children?</p> <p>20) ANNETTE: 13 and 16.</p> <p>21) RESEARCHER: Can you tell me a bit more about how it feels and um I suppose what it's like having HIV?</p> <p>22) ANNETTE: Ya I feel lonely and isolated and trapped</p> <p>23) RESEARCHER: Trapped?</p> <p>24) ANNETTE: Ya because you know I'm always on my own and I'm alone in my own body...I have to think always by myself and I hate it, I hate to be trapped in my own body you know I would prefer to be in prison you know it's like I'm a prisoner in my own body and I'm trapped and the medication is keeping me alive but I can't escape this you know...my life...my HIV...my pain</p> | <p>Not allowed to feel happy</p> <p>Meds provide life with challenges</p> <p>Surviving rather than living</p> <p>Life is like a prison</p> <p>Keeping identity a secret</p> <p>Life is like a prison</p> <p>Trapped</p> |
|--|--|---|

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|---|--|--|
| to prison. She is being 'kept' alive like it's not her choice?? She is alive but she can't live the life she did in the past or wants to in the future. | and the way I live [...] my brain is always working to try to keep me going and I try to be positive because they say that in the support groups and I see some of the ladies there they are so happy and keep positive but you know the medications is different for everybody...for me I'm in pain always and I feel it so I can't forget..I can't forget...how...you know it's not easy to forget about it [...] it's part of my life now...no it is my life and it is me now...ya  |  |
| Constant reminder of her illness despite being well   | 25) RESEARCHER: What was your life and who were you?   | Letting go of past self facilitates change                             |
| Defines her.  | 26) ANNETTE: Shew I don't know anymore...I was um...um...I think I don't know I was more happy and I was free [...] I could do many things...I could have a partner and I could walk around with no pain...free of pain...freedom [...] this thing you know it makes you so tired and stops many things...ya many things in my life [...] I was able to do more things before and I didn't always I wasn't I I didn't have the medication um the pills and um I the doctors and hospitals and tests ya it's all very difficult to be free with these things...I can't do many things...I can't work no job no money earning and not to keep busy...I would like to be more busy sometimes I find my life a bit boring, my life before was more full and now it's empty...well um..well it's it's now got different things in it it's filled with different things but not good things so it's empty of good things I could do everyday in the past...um...so   | Meds give life with challenges   |
| Like she's forgotten who she is.  |  | HIV is who I am  |
| Freedom is taken away and no 'normality'. Less able now   |  |  |
| Restricted by meds and services.  |  | Physical and psychological limitations means different self perception |
| No more job but wants to be busy. Change of emphasis. Life has different things now. Many changes.  | 27) RESEARCHER: Are there any...um...well what is your life filled with now then?  |  |
| Survivor  | 28) ANNETTE: It's filled with um...you know I think it's filled with some good things like hope and because of the medication I have I have I will survive and I'm a survivor...like many other people especially in Africa cannot...[...] they cannot survive and so my life has some hope for living and I am alive and that is wonderful but it's maybe a life in prison..ya...it's similar [...] so um ya my life is now filled with worry about my medication and being at appointments and staying healthy to make sure I don't get sick [...] I sometimes feel like I'm getting somewhere and making progress with this HIV but then I go on the bus and see all the healthy people and I wonder what they are thinking and if they can know I am HIV positive but I know they can't but I feel like like well like they you know..um sometimes it's like people can see me, the real me even though I don't like to disclose my status to everybody...only some people know I'm HIV even my daughter she doesn't know because I think the other kids at school will tease her and you know these kids they can be mean to her and she is s young you | Surviving rather than living   |
| Alive is wonderful. Wouldn't have this if still in Africa   |  | Keeping busy means I can avoid   |
| Hiding her status, fear of disclosure. Shame when in public   |  | I am a survivor  |
| Keeping status secret.  |  | Fear of disclosure   |
| Protecting her  |  |  |

|  |   |                                 |
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| daughter from the stigma and prejudice.  | know she doesn't understand [...] sometimes you know I want to tell people and be free because maybe if I can be honest I can be free but then if I'm honest I might have to go back to my house [...] you know because maybe they will judge me and I hate it...that's why the support groups are helping me so much...because the people there they know...the people they understand and there's no judge you know [...] I er...it's so difficult  | Keeping identity Secret         |
| Stigma.<br>Judgement   |   |                                 |
| Being understood in support groups.<br>No judgement.<br>Feel safe  | 29) RESEARCHER: Who is the real you?  | Refocus onto being a mother     |
| Two 'me's, the illness and the me that's exposed   | 30) ANNETTE: Who is the real me?...um shew...um the real me somebody with an illness that I can't control, I can well I can live with it and be ok but I can't take it away...nobody can take it away so it's there forever now and it means I am different...um ya I I'm in a way I'm different to how I was before because I didn't have this HIV part of me and and um...  | Support groups are valuable     |
| Changes to body and identity   | 31) RESEARCHER: So what does that mean for you now?   | True self vs image they portray |
| Adjustments to life and identity.<br>Become something new.<br>Being in pain is ok because she's not dying. She is still a 'sick' person. | 23) ANNETTE: Well you know it it means well it means that I have to make adjustments and changes to my life...I'm now now I'm not a healthy person but I mean I am because I don't have too much sickness except a lot of pain from the medication but I'm not dying so that's better than before when I didn't have the medicine but I'm still not a healthy person...um...because you know I have this disease that is permanent. You know...you know it's like um...how can I put it...it's like one day you have no child and then nine months later you are a mum and everything has changed...you are now a mum...life is different and you become something new [...] you know what I mean | Identity is a work in progress  |
| Permanent  | 24) RESEARCHER: Yes I do  | Recognising change              |
| Comparative to having a child??<br>New Identity  | 25) ANNETTE: And and now I am a woman with HIV but I wasn't before.<br><br>26) RESEARCHER: So how um...how do you see or view yourself now then?<br><br>27) ANNETTE: Now with the HIV?<br><br>28) RESEARCHER: Yes.  | HIV is who I am                 |
| It's all me, who I am. Defines me  | 29) ANNETTE: Now I am well...you know it's hard to explain it to you and um...this this thing..HIV is a big part now of my existence (sigh) I have to try to fit it into my life...I have to I have no choice...it takes away all my decisions and my choice and forces me to accept it [...] um you see, you know a lot of what I feel and um also   |                                 |
| Well but still HIV. Fit in with life and identity. No choices. No control. Forced  |   |                                 |

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| acceptance.  | what I do is determined by this HIV status so I can't control my life like I used to and I had so many plans and dreams and now it's all gone but at the same time I have life so I have to be thankful to that...I have to thank God I am alive [...] many things have changed [...] now I think life is very short and I'm so thankful for being alive because you know when I first heard about it...um I was so scared...I was so scared...I thought my life was finished and it was the start of my time to die and you know everybody around me was dying and getting sick so I thought it would happen to me but I was lucky...I didn't get too sick except my muscles in my body were so sore and always I was falling and I couldn't even walk some days...um...before in South Africa [...] I remember now...I was so scared but the people were very kind and...ya but anyway...um when I came here and after I got my medication it was better but now I'm still in so much pain...but I'm better than I was and I'm not going to die definitely...maybe but we all will die (laugh) but I have more time now [...] I'm happy I have more time and I can live to see my children get big and can have a future here now...um...England gives them school and a house...it gives us a house and we can survive...but you know if Africa...ya I don't know it's good but you don't get anything and no-one cares that everyone is dying and there is no money for us...er it is very bad...it's very bad there. | Letting go of ideas about past self facilitates change |
| What I am is what I feel. Ruled by the HIV.          |   |  |
| Loss of hopes and dreams so future has changed.      |   |  |
| Appreciative of life and what she has at the moment. |   | Acceptance   |
| Shift in priorities.                                 |   |  |
| Fear of death  |   |  |
| Feels lucky  |   | HIV is who I am  |
| Fear is reduced since moving to England              |   | Value life   |
| We all die. We are all the same.                     |   |  |
| Changed priorities.                                  |   | Priority shift   |
| Feeling valued in UK                                 | 30) RESEARCHER: Can you tell me more about having more time and how that makes you feel?  |  |
|  | 31) ANNETTE: More time...well...um...more time means that I can live longer and that gives me hope...I need hope to be able to keep positive [...] ya maybe that's what the medication gives me is hope and I can keep taking it...but it does make me sick sometimes and so tired and weak...but I need to keep going and fighting this thing but it's so difficult...it's always in my mind and I can't stop it. I want to live a normal life but this HIV makes it impossible because you can't push it away or or you know um...get rid of it   | Normalising  |
| Hope. Needed to be positive. Pros and cons of meds   |   |  |
| Fight  |   | Feeling valued by welfare system                       |
| Conflict between living and life.                    |   |  |
| Can't escape it.                                     |   |  |
| Unavoidable  | 32) RESEARCHER: How have you learned to live with the illness?  |  |
|  | 33) ANNETTE: I don't know if I have (laugh) I just take one day by one day and I survive the day and I try to accept it because I can't change it...the most difficult is when people don't know and I have to hide it...um...that um is hard...I feel frustrated and ashamed when I hear people talking about HIV but not in the support group...it's it's only...um.. it's only really with people who don't know and will think you are bad and dirty and um...what's the word...um...when you can catch it  | Hope   |
| Day by day. Living for the moment.                   |   |  |
| Acceptance   |   |  |
| Frustration, shame                                   |   | I'm a survivor   |
| Bad, dirty   |   |  |

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| <p>Contagious</p> <p>How it is contracted makes a difference.</p> <p>Getting it from husband makes it easier. Less judgment</p> <p>Still me but with HIV. Additional part to me now.</p> <p>Changed who she is.</p> <p>Never be the same</p> <p>Accepted in support groups.</p> <p>Free from her prison</p> <p>Thinks if others have HIV they have the same problems. Identification with group commonality</p> <p>Change for the better. Value what she has got</p> <p>Appreciates life</p> | <p>34) RESEARCHER: Contagious?</p> <p>35) ANNETTE: Yes they think you are contagious and they must stay away (sigh) you know...I I don't like that</p> <p>36) RESEARCHER: No...that must be difficult for you...how does that make you feel about yourself?</p> <p>37) ANNETTE: I know I'm not dirty and you know I only got this thing...um this I got this from my husband and you know I wasn't bad and I didn't go um...er...sleeping with other men...er...so I'm not feeling bad about that and the people who think badly about me...well what can I do? [...] you know it's I'm there's nothing I can do because people will think what they think and so I can't change that either...I can only control what I think...er...and um...well I think I am the same person but with HIV now so I'm not a different person...my my...I'm still me and I have to try to remember who I am and just live with the illness without it changing me too much.</p> <p>38) RESEARCHER: Do you think it has changed you?</p> <p>39) ANNETTE: Of course...er...yes it has [...] I can never be the same but I like I said you know I learn to live with it [...] the support groups help me because I can be understood there and accepted...we there we are all accepted and we don't have to worry about the judgement...um it's it's the place where I can be myself and I don't have to hide...yes maybe it is the one place I am free [...] free from my prison...it helps a lot..ya it does and sometimes I wonder what I would do without these people...these other Africans with the same problems.</p> <p>40) RESEARCHER: Can you tell me any more about how you've changed or um you know how you've changed since learning about your status?</p> <p>41) ANNETTE: Um ya...I can...um...I suppose I'm stronger and wiser and I don't take things for granted as much. Every day is precious now and that's a good thing. I'm definitely more appreciative of life and um the um small things [...] even when I'm not in pain I'm thankful and I notice it...before I won't I wouldn't have been noticing that...I didn't know it was going to change so I I um it's hard to explain [...] I didn't know that being pain free was so precious and so um lucky for me you know I was privileged and now I must try not to be angry or jealous or whatever you know because some people</p> | <p>Life is like a prison</p> <p>Wanting to avoid</p> <p>Defending the identity</p> <p>Value life</p> <p>Support groups are valuable</p> <p>How it is contracted makes a difference</p> <p>Identity is a work in progress</p> <p>Support groups are valuable</p> <p>Life is like a prison</p> |
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| Lucky  | <p>they are quite bitter about it but i must I have to try to move forward and get through the day and notice any good things so I don't always be focus on the bad things [...] maybe that's a big change and I think it's I'm I'm stronger for that [...] but you know it's the support groups that have helped me to do that...and my children because I have I must be strong for them too and I must be a good mum [...] I have HIV but I'm also a mum so I must not let this terrible disease and the medication and all the bad things...you know it must not stop me when I want to be a good mummy...I can't work now you see and I always have to be at an appointment or something or have my medication and and when I um...if I need to work I can't...it stops me so I can't work.</p> <p>42) RESEARCHER: What work have you done in the past?</p> <p>43) ANNETTE: Um...many things because in South Africa I worked for a white family for many years and I was the domestic and they helped me so much and helped for my for my children to go to school and then when that family left to go overseas I found peace work for some years and the um...well that's what i did there but it was not easy you know sometimes I had no work and I had to go home to look after my mother because she was dying...ya she was sick so I went back there and then when she died I got the papers to come to England and my children too...ya [...] thank God for that you know...it was I was lucky...it's not everyone that can come here...I was lucky and but now it's it's I couldn't find a job here and with my HIV I get so much help and they pay for so much...and you know the groups sometimes you can get free food...you know because you came there...you saw...we get so much for nothing but in South Africa...er..no way (laugh) you get nothing...the life there is hard you know...without the job and when you are sick it's so much stress...sorry what was the question?</p> <p>44) RESEARCHER: Oh um well no I was just asking about your work.</p> <p>45) ANNETTE: Ah yes so...um...yes that's what I did but here I can't work.</p> <p>46) RESEARCHER: Okay...um you said you were lucky, can you tell a bit more about being lucky?</p> <p>47) ANNETTE: Ya I am lucky...I'm very lucky...my life is not so bad but I sometimes I have wanted to die...it wasn't always good. I'm lucky to be here and have the medication and my children and the things I get here...it wasn't you know um...it wasn't in the beginning...no...in</p> | Strong sense of community                   |
| Anger  |   | Recognising an altered self                 |
| Jealousy   |   |   |
| Moving forward   |   | I'm a survivor                              |
| Strength from support groups and children  |   |   |
| Motherhood makes her stronger. Will to survive.<br>Can't work, it's a bad thing.     |   | Being a mum makes me stronger               |
| Her jobs.  |   |   |
| Seeing others die  |   | Letting go of past ideas facilitates change |
| Feels lucky to have been able to immigrate.  |   |   |
| Feeling valued by the welfare system and support provided.                           |   | Feeling valued by welfare system            |
| Comparison to SA. Needing a job there but it's not essential for life or death in UK |   |   |
| Loses focus  |   | Support groups are valuable                 |
| Very lucky.  |   |   |
| Wanted to die  |   |   |

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| <p>sometimes but children and meds kept her going.</p> <p>Was different in the beginning.</p> <p>Changed her perception over time.</p> <p>Time helps</p> <p>Being black and discrimination in UK. Prejudice.</p> <p>Visibly unwell in SA. Refers to herself like an animal in zoo. Free to be accepted by other "animals" (people with HIV) SAD! Laughing to disguise pain. Feels caged. Like a prison again. Like she is something worth looking at but people are afraid so she is locked away.</p> <p>I laughed because she was laughing but I was shocked internally</p> <p>Issues with disclosure, particularly in UK.</p> <p>Support groups simulates family and community structure.</p> | <p>the beginning I wasn't lucky I thought I was...why me and how can this be happening but it was also happening all around so it was just one of those things...but here it's not so common so it's harder to accept here but I'm lucky here and in South Africa it was easier to accept and...um...I also...it was more accepted...um...than here but I wasn't so lucky [...] maybe you know it's the change of country that has helped me but also maybe it's time that I have I have I've had time so and I have got better too and those things have helped me to be more lucky...ya</p> <p>48) RESEARCHER: Can you say more about being accepted and not accepted?</p> <p>49) ANNETTE: Ya you know it's not accepted here and people judge...it's always you know black people bring this disease but you know it's not...it's not only...it's all kinds but when you are black and from Africa...shew...I don't know but the people here they judge you. When I was looking very sick in South Africa because I was getting so thin...so thin [...] I was also had I had very bad skin and I was getting darker and the people could see how she has not well [...] that was more normal there so it was sometimes like I was an animal free to walk with the other animals but here you know...(laugh) here it's like I'm an animal in the zoo with the other people with HIV [...] everybody looking at us in the cage and afraid of us (laugh) ya it's like the zoo (laugh)</p> <p>50) RESEARCHER: (Laugh) what a very interesting analogy (laugh)</p> <p>51) ANNETTE: Ya but you know it's true the people know about this thing here...maybe better than in Africa but here they don't accept and it's much harder to...um...to you know to disclose to the people.</p> <p>52) RESEARCHER: What's it like disclosing in South Africa</p> <p>53) ANNETTE: Well I um...you know you are South African it's easier because there are more people there with this and um...yes it's easier there for me to accept it [...] others and me...I can accept better there but then...there I'm not so lucky...I don't know it's difficult...because...it's better here for the medication and help but there I have family and my community to help me so that is like the support group here anyway..ya...I don't know</p> <p>54) RESEARCHER: What would it be like for you living with HIV in South Africa compared with the</p> | <p>Being a mum makes me stronger</p> <p>Identity is a work in progress</p> <p>Two stigmatised identities</p> <p>Life is like a prison</p> <p>Surviving rather than living</p> |
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| <p>Africa would provide freedom.</p> <p>Life is better in SA</p> <p>Stay in UK for children and her health</p> <p>Can't go back to SA.</p> <p>Feeling valued in UK for expensive disease.</p> <p>Survival, moving forward. Accepting</p> <p>Belonging is important.</p> <p>Support groups provide a sense of commonality and belonging.</p> <p>Simulate African community</p> <p>Two stigmatised identities. Black as well as HIV especially in a white country</p> <p>Being white you can hide HIV. Being black exposes her.</p> <p>Stereotype</p> | <p>UK?</p> <p>55) ANNETTE: Um I don't know now [...] I can only think...maybe you know it's free there...we have space and the animals and the organic food and life is better...ya definitely my life there is better...but maybe I would die...that's not better [...] so ya I must stay here and my children must stay here for the school and everything...I don't think about it</p> <p>56) RESEARCHER: You don't think about what?</p> <p>57) ANNETTE: Life in Africa [...] if I think about life there...what for...I can't go back so it's better I don't think [...] you know I go back there...I go back for the holiday sometimes but now it's lots of competition for the jobs and if I have no job I have no money and it's so expensive this disease...very expensive there...I don't have a choice I can't afford it...maybe you know I just I just must learn to move on [...] maybe that's what I've done [...] moving forward it's better (laugh)</p> <p>58) RESEARCHER: It certainly is...um Annette what is your experience of being black African living in the UK?</p> <p>59) ANNETTE: Hmmm...um it's okay [...] I have some friends here form the support group so I can belong to a group which is very important for African people you know (laugh) maybe you know?...well ya...so I have a small community here in the support groups and some of the ladies are also from South Africa and even one she is from Durban and so it is nice for me...the other ladies are from Uganda and Zimbabwe but the African people are usually the same when they come to England...it is we are black and we have HIV so we have both things...both hard things when you come to a white country...you know and the stigma here about black people is terrible...not only the HIV...I don't know about the white people with HIV here but I think it's not so bad for them when they are white...they can hide it because no one knows or thinks oh he must have HIV but you know I know there are many there are people not black here with HIV I know that...um...but we can't know it...with black African people they know it [...] um but really I'm thinking...um...there are actually a lot of black African people in London so that is better. I remember I thought when I first came oh my God what will these English people think about me...but when I came...when I came here there were already so many many African people...for me that was better.</p> <p>60) RESEARCHER: Okay Annette I'm just wondering how much does being black African play a</p> | <p>Fear of disclosure</p> <p>Support groups are valuable</p> <p>Life is like a prison</p> <p>Refocus onto being a parent</p> <p>Lack of control</p> <p>Feeling valued by welfare system</p> <p>I'm a survivor</p> <p>Support groups are valuable</p> |
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| <p>Feels better to have other Africans living in UK.</p> <p>Difficulty understanding question. Term identity is confusing</p> <p>Proud to be African. Strong sense of ethnic identity.</p> <p>It is all she's known</p> <p>God</p> <p>Supportive African culture. Share</p> <p>Hardships lead to strength and survival</p> <p>She sees African as beautiful but at same time others judge it. Confusion.</p> <p>Identity affects her experience of HIV and vice versa.</p> <p>Can't be separated. Identity</p> | <p>part in your identity?</p> <p>61) ANNETTE: Identity?</p> <p>62) RESEARCHER: Ya who you are and how you view yourself.</p> <p>63) ANNETTE: Oh um I don't know...um I think I have...sorry I'm not understanding the question...you want to know about what I think about being black African?</p> <p>64) RESEARCHER: Well yes and if you think it's impacted on you and made a difference to your experience of having HIV?</p> <p>65) ANNETTE: Shew...um..I am black and I am African and it's it means I'm proud you know it is something that I am and I haven't been something else so I don't know...it's like what God gives me I must continue and I must live with...I think it's like that [...] the African culture is very supportive and we have our big family and live together as one and we share but the African people are different to the British because we don't have everything we need and we don't get money and so we are survivors and so maybe I am a survivor for that...ya...maybe...I keep going forward because otherwise we die [...] that is maybe the same for me with this HIV...ya I don't know if it's answering your question?</p> <p>66) RESEARCHER: Yes, thank you but is there any more you can say about that?</p> <p>67) ANNETTE: Um I don't know I'm just African, African is beautiful and African is strong but in the world it's discriminated like so is HIV so maybe both of those things makes a difference to how I am...you know what you said to my identity...ya...I think so</p> <p>68) RESEARCHER: Okay this is a similar question but just the other way around, I'm wondering how being HIV played a part in your identity?</p> <p>69) ANNETTE: Um well it's what I said before it's they are both a part of me and it's they make a um...they affect me both ways...you know one affects...um...HIV affects me and I affect HIV...I mean well my experience of HIV... don't know I can't separate it so HIV is who I am now...ya it's sounds sad you know but ya...I have to change things to fit it into who I am now...it um well I can't be the same now...it's very hard to explain I don't know now what I say...she (laugh)</p> | <p>Acceptance</p> <p>Sense of community</p> <p>Two stigmatised identities</p> <p>True self vs image you portray</p> <p>Africa is strong</p> |
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| and experiences are linked.   | 70) RESEARCHER: (laugh) it's okay...you seem a bit tired?  | Sense of community                         |
| Getting tired   | 71) ANNETTE: ya I am getting tired and I have to take my medication at twelve so I might have to eat a banana with it.   | Africa is strong                           |
| She could demonstrate in the interview how the meds take over her life. | 72) RESEARCHER: That's fine you do that...no problem...does it make you feel sick if you don't eat?  | Identity and experiences impact each other |
|   | 73) ANNETTE: Ya it's very sick...ya it's terrible but that's why we eat so much sometimes with...on the medications...and I take pills for everything so many tablets and not everybody is but for me I take for so much and it's I'm always eating so now I'm getting fat (laugh)...ya but it's better because the doctors tell me I must take it you know for my heart and for my blood pressure and one is for my stress but it's okay it helps me I think...I hope (laugh)   |  |
|   | 74) RESEARCHER: Annette I know you're tired and I don't want to keep you too much longer because you've told me so much and I appreciate...um I appreciate you being so open with me and it's so interesting you know...listening to your experience and what it is like for you.  |  |
|   | 75) ANNETTE: Ya it's okay  |  |
|   | 76) RESEARCHER: I just have a few more questions...is that okay?   |  |
|   | 77) ANNETTE: Ya it's okay.   |  |
|   | 78) RESEARCHER: What has helped you to come to terms with your diagnosis?  |  |
| Acceptance. God. Support groups help her to cope.                       | 79) ANNETTE: Um I have to accept...to accept...move forward...pray to God and definitely the support groups [...] they teach me better ways to cope with things everyday and make me feel less alone...this disease makes you feel so alone sometimes and that is so so bad...the support groups help that...um...I don't know [...] maybe that I am lucky to be alive still and everyday is more than so many people back in Africa have...ya I'm a lucky one and it's taught me to be grateful and notice the small things...I what's it how do you say...um...I value the life more...now...ya I think that is making me a better person so maybe in that way...ya it's a good thing...ya | Meds give a life with challenges           |
| Less lonely   |  |  |
| Feeling lucky in comparison to others in Africa                         |  |  |
| Her experiences have led her to perceive life and                       | 80) RESEARCHER: Are there any particular strategies or personal strengths that help you?   |  |

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| self differently.   |  |  |
| Motherhood. Faith.  | 81) ANNETTE: My children...I think my children and my faith and that I can't control it...I don't like it but I can't control so I must accept...maybe if I have control I can fight it but with HIV there is no choice and you can't change it so you must let go...but ya..that's hard [...] hard at first but it gets easier  |  |
| Loss. Letting go of what she cannot change.   | 82) RESEARCHER: How?   |  |
|   | 83) ANNETTE: I don't know...time...some thinking and maybe talking in the support groups   |  |
| Reflection is helpful   | 84) RESEARCHER: Are there any emotional or psychological you know mental forms of coping?  | Acceptance   |
| Talking helps   | 85) ANNETTE: Ya I think maybe to be keeping busy because sometimes you can think too much and that's not good...it's impossible to get this thing out of my mind...you know and it's the same I know for everyone...it's always there...it can't go away from my brain but sometimes if I am busy it's helping me [...] also maybe being with control when you can like going to appointments and support groups and the doctor and to take the medication and be a good mum and be thinking about what you can control...that makes it easier...ya...I think that definitely helps me [...] I can't do many things anymore, no job, no partner, no freedom, always pills and not to keep busy is bad because you know sometimes I find my life bad like I would in prison, my life before was more full and now it's empty, well I don't know I suppose it's filled with different things...yeah that's all can say about that, yeah, um I think. | Support groups are valuable                                |
| Being active means she can avoid dwelling on her circumstances and continue living. |  | Value life   |
| A way of regaining control  |  | Recognising an altered identity                            |
| Loss of aspects of her life she had prior to diagnosis.                             | 86) RESEARCHER: Annette in terms of your psychological strategies of coming to terms with HIV, can you tell me a bit about that?   | Being a mum makes me stronger                              |
| Change of aspects of life and identity.   | 87) ANNETTE: Umm yeah you know we don't normally we're not talking about these things, it's not like England with talking of the feelings so I'm not sure we just get on with it because it is this things and what can I do?  | Letting go of past ideas about the self facilitates change |
| 'We' as Africans don't talk about problems. Unlike in England                       | 88) RESEARCHER: Okay   |  |
| Africa has less   | 89) ANNETTE: You know I don't know why but I think maybe it is because in Africa there is not so much money and so the life is tough there and I see now, I learn how many people in England think it's so important to talk about what is going on and I think it's good and we do this a little bit in the support groups but I don't think I would go and see the counsellor because it's like  | Keeping busy helps to avoid                                |

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| <p>money for talk therapies</p> <p>Poverty makes life tough.</p> <p>Feels a lack of empathy from a counsellor. Better to relate to people with similar experiences.</p> <p>Being taught to be strong since a child. Values her mother's lessons.</p> <p>Community life, maybe it replaces a need to talk about problems</p> <p>Independence is not the norm in her culture but she appreciates being taught how to be independent. She can use it now to better manage her life.</p> <p>Survivor. Winning a fight with the disease.</p> <p>One day at a time.</p> <p>Don't think about the future. Less certainty.<br/>Hoping to see her daughter develop through different milestones.</p> | <p>you know, they don't know as well as the people. I really really like the support, um, yeah um the groups you know because we can just know that we have support. I don't always need to say it but we just know and I think maybe that is the same with British people. I remember when I was a little girl and my mummy would say that I must be strong and be tough because maybe no one is there to help me when my family is gone but then I remember I couldn't understand it because why? I say my gosh "why would I not have family, ever, why?" That does not seem possible because the family is so big and we have a big community but now, wow I think maybe she knew something then. My mum she was also a strong lady and she taught me a lot about being strong myself and what's what's the word, um independence you know independence is so important but it's not normally like that in South Africa with the people there. But here yes I'm so glad she taught me that because I think I am able to continue and try to make new friends and do what I have to do to survive, even I am alone sometimes, I am strong and I can survive. Yeah my mother she taught me to believe in what I can overcome. Yeah that's what I think.</p> <p>90) RESEARCHER: What beliefs do you have about yourself or life?</p> <p>91) ANNETTE: A survivor...I am a survivor...I am winning this fight with my HIV...for now and so I try to think well and good thoughts even though the pain and you know also we have good and bad days...always so just get through each day and then tomorrow you might...it might be a better day..and you know you will then you know you got through it (smile)</p> <p>92) RESEARCHER: How wonderful (lump in throat)...um Annette what do you think your future will look like?</p> <p>93) ANNETTE: I don't know...I don't think too much about the future but if you ask me now...um I suppose it will be there...I hope I will live a long time to see my children...maybe my daughter when she gets a boyfriend and maybe she will even go to university I don't know...for me I don't know.</p> <p>94) RESEARCHER: Do you think the way you view yourself changes and might change in the future?</p> <p>95) ANNETTE: Um I don't know that either...I think we change...I think I have changed and I don't know why or what happens but we change when we get older...the life makes us change and adapt to...so we can survive...it's like the animals...like the animals in</p> | <p>Regaining control</p> <p>Letting go of past ideas of self facilitates change</p> <p>Not psychologically minded</p> <p>Africa is strong</p> <p>I'm a survivor</p> <p>Sense of Community</p> |
|---|---|---|

|  |  |  |
|--|--|--|
| <p>Even after all the change she's experienced she's unsure she'll change in future??</p> <p>Normalising change.</p> <p>Adaptation.</p> <p>Expressing that she could say more. For me to know it's a complex topic. Not familiar with taking about certain of these things. Acknowledges the purpose of the research.</p> <p>Doesn't feel bad, maybe she expected to?</p> <p>Feels good.</p> <p>African connection was acknowledged.</p> | <p>Africa...it's the nature.</p> <p>96) RESEARCHER: That's a very interesting analogy (laugh) I like it.</p> <p>97) ANNETTE: Well it's true.</p> <p>98) RESEARCHER: Is there anything else that you you'd like to share with me to help me understand your experience?</p> <p>99) ANNETTE: Probably but we would be here for a long time (laugh) no I think that is everything. I'm quite tired and I can't think anymore about anything else. Some of these things I haven't really talked about before.</p> <p>100) RESEARCHER: I appreciate your time, I really do. What has it been like talking to me today?</p> <p>101) ANNETTE: Good actually because I don't feel bad. I actually feel okay and well I'm hungry but it's lunch time (laugh). No it's been okay and it's for a good purpose, I think.</p> <p>102) RESEARCHER: Yes I like to think it is.</p> <p>103) ANNETTE: Thank you.</p> <p>104) RESEARCHER: Thank you Annette...it's been an absolute pleasure speaking to you and I thank you so much for coming to meet with me...you are a very strong lady...</p> <p>105) ANNETTE: Thank you...</p> <p>106) RESEARCHER: But then again you are African (laugh)</p> <p>107) ANNETTE: (laugh) yes...I am African [...] oh we are African (laugh)</p> | <p>Independence</p> <p>I'm a survivor</p> <p>Value life</p> <p>Uncertainty of future</p> <p>Normalising</p> <p>Africa is strong</p> <p>African pride</p> |
|--|--|--|

#### ***Appendix 14: Reflections of Annette's interview from reflexive diary- example section***

Being aware of the difficult nature of the topic, I was very sensitive to the needs of all participants and tried to make Annette feel comfortable and as relaxed as possible. This was also because she appeared nervous and apprehensive so I reassured her that she did not need to talk about anything she did not want to talk about. I was aware of how I might be perceived by Annette considering our common nationality but very different culture and lived experiences. This interview (like some of the others) really made me feel sad because the way she spoke about her strength despite having to face up to such harsh realities, both now and in her past was awe-inspiring to me. Perhaps I felt more emotional than others might have because it reminded me of previous experience working with individuals with HIV in South Africa. I felt then and feel now so removed from the world that so many of these women come from even although I grew up in the very same country (as Annette). I felt sad because the Western world which is echoed in part of South African culture among much of the higher socio-economic population, is not in touch with the experiences and challenges other human beings are faced with when they are born into a poorer or different socio-economic class. I felt a sense of patriotism for my country through Annette's expression of strength and it seemed as though she might have shared that with me which enabled her to feel more relaxed. As many of the women have said, sharing and a sense of commonality helps them to feel strong. Perhaps this dynamic was being played out with me in the interview. I am a very proud South African and I feel passionately about the voices of the oppressed being heard. Despite the many positive changes in South Africa, there is still so much which can be done to improve the lives of the less advantaged.

Annette seemed to move from taking quite a negative outlook to a more positive stance as the interview progressed. She appeared to feel more and more relaxed throughout in terms of body language and being able to express her feelings, for example, she was open and honest about feeling tired and comfortably informed me of her need to take her medication. There was a sense that Annette's identity shifted even within the interview depending on what she was talking about. This suggested that identity is fluid and flexible. I felt I needed to follow her through her descriptions of her own journey of how she perceives herself. Sometimes her facial expressions and pauses suggested that she was thinking a lot about what I had asked and how she could conceptualise her experiences. At the end she looked and seemed happier than when she arrived which was not always the case with the other participants. Perhaps this too says something about how one's identity is individually shaped depending on existing identity and previous experience as well as perceptions about how the outside world perceived them. I felt as though Annette felt listened to and perhaps felt valued by being given an opportunity to be heard. However this belief or perception may have been a reflection of my own identity and needs.

## ***Appendix 15: Paper Trail***

### List of emerging themes- in chronological order: Annette Interview

| Emerging Theme   | Line Number                                      |
|--|--|
| Being a mum gives strength   | 6-8, 277-281, 316, 501-502                       |
| Letting go of past ideas of the self that no longer fit                | 12-15, 288-305, 501-505, 524-529                 |
| Meds provide life with challenges                                      | 28-36, 40-47, 85-94, 98-112, 340-342, 463-469    |
| Not allowed to feel happy  | 40-47, 51-58                                     |
| Life is like a prison  | 51-58, 77-94, 213-215, 254-256, 339-342, 364-369 |
| Keeping identity a secret  | 62-64, 124-140                                   |
| Letting go of past self facilitates change                             | 90-94, 98-112, 175-185                           |
| HIV is who I am  | 92-94, 167                                       |
| Keeping busy means I can avoid   | 121-123, 515-523                                 |
| Physical and psychological limitations means different self perception | 98-112   |
| I am a survivor  | 117-118, 211-215, 379-380, 562-566, 570-575      |
| Fear of disclosure   | 124-137, 353-359                                 |
| Shift focus onto being a mother  | 130-140, 367-369, 580-584                        |
| Support groups are valuable  | 137-140, 222-224, 251-258, 359, 385-406, 486-490 |
| True self vs image they portray  | 128-129, 142-145, 395-400                        |
| Identity is a work in progress   | 153-163, 242-246, 323-327                        |
| Recognising an altered identity  | 146-149, 263-276, 496-496                        |
| Acceptance   | 175-182, 321-323, 386, 486                       |
| Value life   | 182-198, 219-220, 491-494, 573-575               |
| Priority shift   | 196-200  |
| Normalising  | 195-197, 589-592                                 |
| Feeling valued by welfare system                                       | 198-203, 297-305                                 |

| Emerging Theme                             | Line Number                             |
|--|---|
| Hope                                       | 208-211                                 |
| Wanting to avoid                           | 221-226                                 |
| Defending the identity                     | 224-225                                 |
| How it is contracted makes a difference    | 236-239                                 |
| Strong sense of community                  | 276, 385-406, 547-557                   |
| Two stigmatised identities                 | 333-335, 392-406, 437-440               |
| Lack of control                            | 376-380                                 |
| Africa is strong                           | 422-433, 437-440, 426-432, 542, 551-553 |
| Identity and experiences impact each other | 445-451                                 |



### Emerging themes – All interviews

|  |  |
|--|--|
| Being a mum gives strength   | HIV salience changes depending on health                             |
| Letting go of past ideas of the self that no longer fit                | Wanting to express herself   |
| Meds provide life with challenges                                      | Talking as an outsider   |
| Not allowed to feel happy  | Genuine vs fake  |
| Life is like a prison  | Staying alive and well is a full time job                            |
| Keeping identity a secret  | Freedom to disclose regains control                                  |
| Letting go of past self facilitates change                             | Avoidance  |
| HIV is who I am  | A need to rebuild the self   |
| Keeping busy means I can avoid   | Acceptance vs control  |
| Physical and psychological limitations means different self perception | Externalising HIV  |
| I am a survivor  | Rejection projection   |
| Fear of disclosure   | Assumptions fuel fear  |
| Shift focus onto being a mother  | 'Insider' support  |
| Support groups are valuable  | Disclosure: damned if I do, damned if I don't                        |
| True self vs image they portray  | Only control is to take control                                      |
| Identity is a work in progress   | Meds give control  |
| Recognising an altered identity  | Resilience to identity shift   |
| Acceptance   | Maintain identity means maintain control                             |
| Value life   | War against HIV or war against identity shift                        |
| Priority shift   | Integration  |
| Normalising  | Ethnic identity strengthens when away from home                      |
| Feeling valued by welfare system                                       | Physical and psychological limitations means uncertainty over future |
| Hope   | Refusing to die  |
| Wanting to avoid   | Superficial vs real  |
| Defending the HIV identity   | Appearance is everything   |
| How it is contracted makes a difference                                | A new me   |
| Strong sense of community  | Stigma and prejudice prevents honesty                                |
| Two stigmatised identities   | Internal battle  |
| Lack of control  | Maintaining image that fits with community values                    |
| Africa is strong   | Medication disrupts living   |
| Identity and experiences impact each other                             | Family support   |
| Not a person anymore   | Focus on physical health over mental health                          |
| Practical strategies of coping   | Fear of death  |
| Uncertainty  | Adhering to meds   |
| Medical treatment is unfamiliar  | Hardships have made me tough   |

### Initial Clustering of Themes – All interviews

|  |   |
|--|---|
| <b>Strength/Refusing to die</b><br>Being a mum gives strength<br>I am a survivor<br>Shift focus onto being a mother<br>Support groups are valuable<br>Feeling valued by welfare system<br>Hope<br>How it is contracted impacts strength<br>Strong sense of community<br>Africa is strong<br>'Insider' support<br>Ethnic identity strengthens when away from home<br>Family support<br>Hardships have made me tough | <b>Acceptance</b><br>Priority shift<br>Lack of control<br>Acceptance vs control<br>Only control is to take control<br>Meds give control<br>Uncertainty over future  |
| <b>Avoidance</b><br>Keeping busy means I can avoid<br>Normalising<br>Defending the HIV identity<br>Only practical strategies of coping<br>Talking as an outsider<br>Externalising HIV<br>Resilience to identity shift<br>Appearance is everything<br>Focus on physical health over mental health<br>Fear of death  | <b>Integration/Disclosure</b><br>Keeping identity secret<br>Fear of disclosure<br>Managing two stigmatised identities<br>Wanting to express the self<br>Freedom to disclose regains some control<br>Rejection projection<br>Assumptions fuel fear<br>Damned if I do, damned if I don't<br>Maintain identity means maintain control<br>Stigma and prejudice prevents honesty |
| <b>HIV part of identity- salience</b><br>HIV is who I am<br>Not a person anymore<br>HIV salience changes depending on wellness<br>War against HIV or war against Identity shift  | <b>A need to rebuild the self</b><br>Letting go of past ideas of the self that no longer fit<br>Limitations means different self perception<br>Identity is a work in progress<br>Recognising an altered identity<br>Value life<br>Identity and experiences impact each other<br>A new me  |
| <b>Genuine vs fake</b><br>True self vs image portrayed<br>Superficial vs real<br>Maintaining an image that fits with community values  | <b>Medication disrupts living</b><br>Meds provide life with challenges<br>Not allowed to feel happy<br>Life is like a prison<br>Uncertainty<br>Medical treatment is unfamiliar<br>Staying alive and well is a full time job<br>Internal battle<br>Having to adhere to meds  |

Second clustering of themes – all interviews

|   |  |
|---|--|
| <p><b>Strength/Refusing to die</b><br/>         Being a mum gives strength<br/>         I am a survivor<br/>         Shift focus onto being a mother<br/>         Support groups are valuable<br/>         Feeling valued by welfare system<br/>         How it is contracted impacts strength<br/>         Strong sense of community<br/>         Africa is strong<br/>         'Insider' support<br/>         Ethnic identity strengthens when away from home<br/>         Family support<br/>         Hardships have made me tough</p> | <p><b>Integration/ disclosure</b><br/>         Keeping identity secret<br/>         Fear of disclosure<br/>         Managing two stigmatised identities<br/>         Wanting to express the self<br/>         Freedom to disclose regains some control<br/>         Rejection projection<br/>         Assumptions fuel fear<br/>         Damned if I do, damned if I don't<br/>         Maintain identity means maintain control<br/>         Stigma and prejudice prevents honesty<br/>         True self vs image portrayed<br/>         Superficial vs real<br/>         Maintaining an image that fits with community values</p> |
| <p><b>Avoidance</b><br/>         Keeping busy means I can avoid<br/>         Normalising<br/>         Defending the HIV identity<br/>         Only practical strategies of coping<br/>         Talking as an outsider<br/>         Externalising HIV<br/>         Resilience to identity shift<br/>         Appearance is everything<br/>         Focus on physical health over mental health</p>   | <p><b>Recognising an altered identity</b><br/>         Priority shift<br/>         Letting go of past ideas of the self that no longer fit<br/>         Limitations means different self perception<br/>         Identity is a work in progress<br/>         Recognising an altered identity<br/>         Value life<br/>         Identity and experiences impact each other<br/>         A new me<br/>         HIV is who I am<br/>         Not a person anymore</p>  |
| <p><b>Given life but can't live</b><br/>         Uncertainty over future<br/>         Acceptance vs control<br/>         Meds provide life with challenges<br/>         Not allowed to feel happy<br/>         Life is like a prison<br/>         Uncertainty<br/>         Medical treatment is unfamiliar<br/>         Staying alive and well is a full time job<br/>         Internal battle<br/>         Having to adhere to meds</p>  |  |

### Third clustering of themes – all interviews

|  |  |
|--|--|
| <p><b>Given life but can't live</b></p> <p>"...there's a constant internal battle that goes on with myself"</p> <p>Medication: Friend or foe?</p> <p>"Life is like a prison"</p> <p>What was once taken for granted can no longer be relied upon</p> | <p><b>A will to survive</b></p> <p>"That's strong minded is what it is, Africa is strong."</p> <p>"The doctor, the social worker, everyone (...) help me to survive"</p> <p>Knowledge is power: "they are ignorant about HIV"</p> <p>"I have HIV but I'm also a mum"</p> |
| <p><b>Avoiding the unavoidable</b></p> <p>Doing vs Being</p> <p>Attempt to normalise</p> <p>"My body is shining, you can't even know I'm positive."</p>  | <p><b>Negotiating a stigmatised identity</b></p> <p>Keeping the identity secret</p> <p>"We are black and we have HIV so we have both hard things"</p>  |
| <p><b>Recognising a new me</b></p>   |  |

**Appendix 15: Final master themes and sub-themes**

| <b><u>Super-ordinate themes</u></b> | <b><u>Sub-themes</u></b>   |
|-------------------------------------|--|
| Given life but it's a struggle      | "...there's a constant internal battle that goes on with myself" (Melitta) |
|                                     | Medication: Friend or foe?   |
|                                     | "Life is like a prison" (Annette)  |
|                                     | Letting go of who I was  |
| A will to survive                   | "That's strong minded is what it is, Africa is strong." (Lukiya)           |
|                                     | The value of support groups  |
|                                     | Defending against social stigma  |
| Positive coping                     | Doing vs Being   |
|                                     | "My body is shining, you can't even know I'm positive." (Soffia)           |
| Negotiating a stigmatised identity  | Keeping the identity secret  |
|                                     | "We are black and we have HIV so we have both hard things" (Annette)       |
| Recognising a new me                |  |